Opportunities to improve palliative care: towards a more patient-centred and proactive approach

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OPPORTUNITIES TO IMPROVE PALLIATIVE CARE

Towards a more patient-centred and proactive approach

Mary-Joanne Verhoef

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Opportunities to improve palliative care: towards a more patient-centred and proactive approach

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O weiter, stiller Friede!
So tief im Abendrot.
Wie sind wir wandermüde -
Ist dies etwa der Tod?

Uit *Im Abendrot* (Joseph von Eichendorff/Richard Strauss)

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CHAPTER 1

General introduction

1. PALLIATIVE CARE AND ITS RATIONALE

Palliative care aims to ‘*improve the quality of life of patients and their families, who are facing a life-threatening condition or frailty, through prevention and relief of suffering by means of early identification and careful assessment, and treatment of problems of a physical, psychological, social and spiritual nature. Over the course of the illness or frailty, palliative care aims to preserve autonomy, access to information and the opportunity to make choices*.’ This definition was published by the Netherlands comprehensive cancer organisation (IKNL) in 2017 and is based on the World Health Organisation (WHO) definition from 2002.[1, 2] Ideally, palliative care is integrated into standard care timely during the illness trajectory, and is deemed appropriate to prepare patients and their family for the end of life, in the near or far future.[1, 2] Palliative care is often referred to as an *approach*, rather than a medical specialism.[1, 3] The Dutch Quality Frame work on Palliative care characterises palliative care as follows:

- palliative care can be provided **concurrently** with disease-modifying treatment;
- generalist healthcare professionals and, when required, specialist healthcare professionals and volunteers, work **together** as an interdisciplinary team with patients and their family to tailor treatment to the needs, wishes and values of the patient;
- to ensure continuity, care is **coordinated** by one central healthcare professional;
- the wishes of patients and their family about dignity are **acknowledged** and **supported** throughout the disease trajectory and the process of dying and after death.[2]

IKNL underlined the need of palliative care in their nation-wide report published in 2014: the most common causes of death in the Netherlands are non-sudden conditions, which are indications for initiating palliative care.[4] In 2017, 105.766 patients in the Netherlands died of non-sudden causes. It is estimated that the proportion of non-sudden deaths is around 70% of all deaths (sudden and non-sudden deaths). People who died non-suddenly most frequently died because of cancer (44%), organ failure (25%) or dementia (11%).[5]

The number of non-sudden deaths will further increase due to ageing, improved life expectancy in general and increase in numbers of patients with chronic conditions.[4] The population that is 80 years or older accounts for 4.5% of the total Dutch population. In the Netherlands, life expectancy increased from 72 years for men and 79 years for women in 1980, to 80 and 83 years respectively in 2018.[6] In 2019, the Lancet Commission on Palliative Care and Pain Relief published a paper stating that in 2060, 47% of all people will die after a period of serious health-related suffering. In 2060, the increase in serious health-related suffering will be mostly due to cancer and dementia.[7]

1.1 Early integration of palliative care

Accumulating evidence shows that a palliative care approach can improve the quality of life of patients and their families. In 2016, Kavalieratos et al. published a systematic review and meta-analysis including 43 randomised controlled trials on the association between palliative care and outcomes of patients and their family. They demonstrated that palliative care improves patients' quality of life, which was clinically significant after one and three months of follow up. Other effects of palliative care include reduced symptom burden, more occurrence of advance care planning, improved patient and care giver satisfaction, and less use of healthcare resources.[8]

Several randomised controlled trials have shown the benefits of early integration of palliative care into standard care. A Cochrane review from 2017 on the effect of early palliative care provided by specialised palliative care teams for adults with advanced cancer demonstrated that early palliative care improved health-related quality of life and reduced symptom intensity.[9] A more recent Belgian randomised controlled trial showed that systemic integration of palliative care into oncologic care versus standard oncologic care improved quality of life after twelve weeks in patients with cancer with a life expectancy of twelve months.[10] Patients who received early palliative care reported a better quality of life six months and one month before they died, compared to patients who received standard care.[11]

1.2 The quality of end-of-life care

Early integrated palliative care should be available for each patient because it can prevent sub-optimal and inappropriate care. De Schreye et al. defined inappropriate care as '*treatment and/or medication in which the expected health benefit (e.g., increased life expectancy, improved functional capacity) does not exceed the expected negative consequences (e.g., morbidity, anxiety, pain) by a sufficiently wide margin that the procedure is worth doing, exclusive of cost*.'[12]

Earle et al. formulated quality indicators for studying end-of-life care in cancer patients.[13] Their four major categories of poor-quality end-of-life care are:

- initiation of a new anti-tumour regimen or continuing current treatment until near death;
- recurrent visits to the emergency department, hospitalisations, admissions to the intensive care unit near death;
- no or late enrolment in hospice care;
- death in an acute hospital setting.

The use of healthcare resources increases in the last phase of life. A study on healthcare utilisation in the last month of life by all Dutch patients who died of or with cancer in 2017, showed that palliative care provided by clinicians not specialised in palliative care was registered in 39% in the last year before death. This study further demonstrated that 34% of patients received potentially inappropriate end-of-life care in the last month of life according to Earle's quality indicators: 5% received chemotherapy, 6% were admitted to the intensive care unit, 8% spent more than fourteen days in-hospital, 9% were hospitalised twice or more often, 12% had visited the emergency department more than once and 20% died in-hospital. Potentially inappropriate end-of-life care occurred five times less in patients who received palliative care at least thirty days before death.[14, 15] A study on medication use in the last days of life in the Netherlands reported that 27% of the patients still were prescribed preventative medication on the day they died.[16] Another Dutch study found that clinicians order less diagnostic procedures and prescribe less preventive medication in the last 72 and 24 hours before the patient dies if they are aware of the patient's impending death.[17]

Randomised controlled trials conclude that integration of specialist palliative care can prevent inappropriate care at the end of life. Temel's landmark study from 2010, in which 151 patients with metastatic non-small-cell lung cancer were randomised to palliative care plus standard oncological care or standard care alone, showed that in patients receiving palliative care, end-of-life care was less aggressive according to Earle's quality indicators.[18, 19] Maltoni et al.'s randomised controlled trial reported that 107 patients with advanced pancreatic cancer who received palliative care (versus standard oncologic care, n=100) were admitted to a hospice more often, were in hospice care for a longer period and underwent chemotherapy less often in the last thirty days of life.[20]

2. PALLIATIVE CARE IN THE NETHERLANDS

2.1 The generalist plus specialist palliative care model

In the Netherlands, 32% of the patients die at home and 25% die in the hospital.[5, 21] Many healthcare professionals provide care to patients who are in the last phase of life and their family. It is warranted that all healthcare professionals working with vulnerable patients are aware of the benefits of palliative care integrated into standard care for quality of life and prevention of inappropriate end-of-life care. Also, they should know their own role in providing such care. To improve palliative care provision among all healthcare professionals, palliative care in the Netherlands is organised in line with Quill and Abernethy's concept of generalist (or: primary) palliative care plus specialist palliative care.[22]

Healthcare professionals providing generalist palliative care are those who have basic knowledge and skills in providing palliative care. This includes basic management of pain and other symptoms; basic management of depression and anxiety; and basic ability to have conversations about prognosis, goals of treatment, suffering and code status. Specialist palliative care is the responsibility of clinicians specialised in palliative care. They manage refractory pain or other symptoms; manage more complex depression, anxiety, grief, and existential distress; assist with conflict resolution regarding goals or methods of treatment; and assist with addressing cases of near futility. Both generalist and specialist palliative care are provided with a multi-dimensional perspective. Responsibilities of generalist and specialist palliative clinicians are described by Henderson et al.[23] From January 2017, every hospital in the Netherlands proving oncological care has a palliative care consultation team.[24] Specialist palliative care consultation teams support patients, family and primary care teams. They also have nonclinical responsibilities, such as teaching generalist palliative care clinicians, reporting delivered care and conducting or participating in palliative care research.[4, 23]

From 2014 to 2020, the Dutch government funded the National Palliative Care Programme called *Palliantie, meer dan zorg*.[25] This programme aimed to raise awareness and guarantee good palliative care for every citizen in the right place and at the right moment and provided by the right healthcare professionals. Themes of the *Palliantie* programme were awareness and culture; organisation; continuity of care; care-related interventions; and patient participation.[26] These themes are worked on within three main pillars: research; education; and implementation. *Palliantie* has made it possible to further develop tools to improve identification of palliative care needs, care for family, advance care planning and a care protocol for the dying phase.[4] Consensus-based guidelines have been developed. Lastly, support for healthcare professionals working in general practice and in hospitals by specialist palliative care consultation teams has been initiated.

2.2 Education on palliative and end-of-life care

Studies performed in the United Kingdom, Switzerland, Germany, and the United States of America have shown that medical students do not feel prepared and lack essential knowledge and skills to provide palliative or end-of-life care.[27-30] The quality of palliative care or end-of-life care education in the compulsory medical curricula has been evaluated in several European countries. These evaluations have led to recommendations to change compulsory curricula, for example by adding internships in hospices and teaching more theory about care for patients in the palliative phase.[28-33] A systematic review published in 2015 demonstrated that compulsory palliative or end-of-life care education varies in quantity and quality across European countries. The authors advised education programmers to include interdisciplinary education and to integrate palliative care education longitudinally through the medical curricula.[34]

The generalist plus specialist palliative care model requires that all healthcare professionals should at least be educated to provide palliative care on a generalist level.[22, 23] In 2009, centres of expertise in palliative care in the Netherlands published their assessment on palliative care in general education of healthcare professionals. Medical curricula were not reviewed. They found only few pre-defined endpoints, even for education for medical specialists in training.[35] Competencies for healthcare professionals working in palliative care were formulated in the COMPARE! Project, which was finished in 2013.[4, 36] A Dutch study among nurses demonstrated that 75% felt they need more education about subjects related to care for the dying. Subjects they most needed education on were knowledge of dying in other cultures; juridical aspects of euthanasia and assisted suicide; palliative sedation; providing support in coping with approaching death or saying goodbye; and decision-making at the end of life.[37] Knowledge and skills regarding palliative care of Dutch medical doctors had not been assessed in detail yet. A study from 2009 showed that 30% of Dutch medical doctors have insufficient knowledge about pain treatment.[4] Medical doctors often consult a colleague or pharmacist for complex cases of pain; 40% reported never having consulted a palliative care consultation team. Additional education about the use of opioids, pain treatment and palliative sedation was appreciated by 83% of the medical doctors in this study.[38]

The *Palliantie* programme characterised palliative care education as one of three main pillars in improving palliative care.[26] IKNL indicated that palliative care generalists lack knowledge and skills regarding palliative care. Barriers to providing quality palliative care were, amongst others, that healthcare professionals did not identify the palliative phase, did not perform advance care planning, and had limited expertise in generalist palliative care.[39] Generalist healthcare professionals should be educated in how to identify patients with palliative care needs. Using criteria for referral to specialist palliative care, or using tools such as the Surprise Question, can help to timely identify patients with palliative care needs.[40]

3. IDENTIFICATION OF PATIENTS WITH PALLIATIVE CARE NEEDS

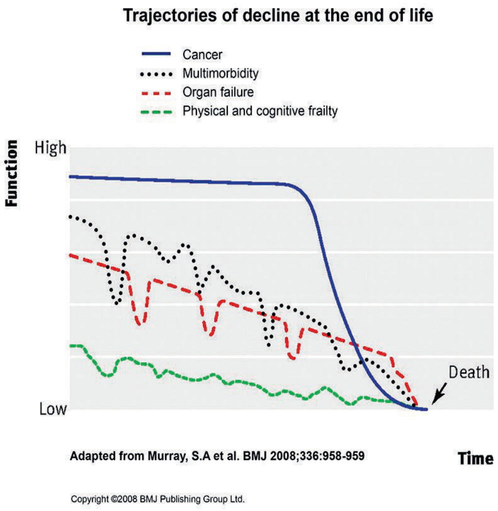
Early identification of patients who may benefit from a palliative care approach is essential in achieving better quality of life.[41] There are several approaches that are helpful to identify patients with possible palliative care needs:

- Recognition of illness trajectories in palliative care (see 3.1)
- Recognition of trigger moments (see 3.2)
- Estimation of the patient's functioning and other clinical characteristics (see 3.3)
- Estimation of life expectancy (see 3.4)
- Use of the Surprise Question (see 3.5)
- Use of tools combining identification methods (see 3.6)

3.1 Recognition of illness trajectories in palliative care

Murray et al. described trajectories of functional decline of three main illness categories (Fig. 1).[42] In trajectories of incurable cancer, patient functioning remains fairly stable for weeks to years until a steep decline occurs in the last phase of life. During the stable phase, palliative care can prepare patients and their family for the last phase of life. The second category of trajectories includes functional decline with intermittent serious episodes, such as exacerbations of chronic obstructive pulmonary disease and heart failure. The patient's functioning can improve after each episode with adequate treatment, but the level of functioning will not be at the same level as before the episode. At some point, a patient will not be able to recover from the exacerbation because of organ failure, resulting in rapid decline and death. Palliative care can prepare patients and their family for the last phase of their disease trajectory when they reach the terminal stage of their condition, e.g., GOLD stadium IV in patients with chronic obstructive pulmonary disease, or NYHA class IV in patients with heart failure. The third category of trajectories concerns frailty and dementia, characterised by a gradual functional decline, leading to death from old age or frailty of the brain and other organs. Since these trajectories can take years, there are several possibilities to timely prepare patients and their families from the moment of diagnosis of dementia, or when functional decline presents.

Murray also graphed the trajectory of multidimensional palliative care needs for these three disease trajectories: physical, social, spiritual, and psychological.[44]



Adapted from Murray, S.A et al. BMJ 2008;336:958-959

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Fig. 1. The three main trajectories of decline at the end of life. From Murray S A, Sheikh A. Care for all at the end of life BMJ 2008; 336 :958, Figure 1.[43]

The palliative care "trajectory" model by Lynn and Adamson shows three phases within a palliative care trajectory (Fig. 2):

- disease-modifying phase, in which treatment is directed at slowing down the incurable disease;
- symptom-management phase, in which treatment is aimed at symptom-relief and supportive care;

- terminal phase, which is multi-dimensional care in the dying phase including bereavement care.[45]

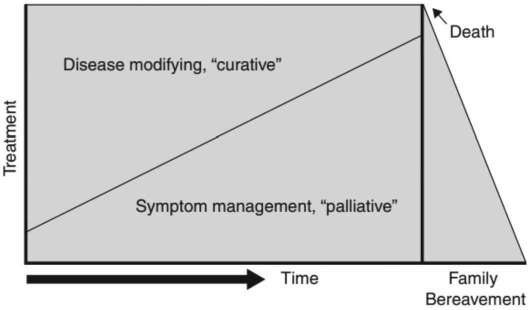

Fig. 2. A trajectory model of care. From Lynn, J. and D. M. Adamson (2003). Living Well at the End of Life. Adapting Health Care to Serious Chronic Illness in Old Age. RAND Health. Santa Monica, United States of America: 18, Figure 2. The Older "Transition" Model of Care Versus a "Trajectory" Model.[46]

This model provides an easy way to understand how a treatment trajectory gradually becomes more focused on supportive care and eventually on bereavement care. The model can be applied to many life-shortening conditions. There are however some exemptions. For instance, illness trajectories of patients with a haematological malignancy are more complex and the timing to assess palliative care needs can be difficult.[47] Haematological malignancies follow unpredictable trajectories which require very toxic curative treatments. In other words, patients not only have a high risk to die of their illness, but also of treatment. Along the illness trajectory, treatment is often with curative until the last days before death.[48]

3.2 Recognition of trigger moments

Illness trajectories and functional decline are accompanied with healthcare transitions, such as increased healthcare utilization and unplanned hospitalisations.[49, 50] Such trigger moments can be used to identify patients with palliative care needs.[51, 52] Trigger moments occur for example when cancer becomes incurable, or when patients and family receive bad news. Palliative crises can occur as trigger moments as well: patients suffer from uncontrollable symptoms or acute severe symptoms; family caregivers are exhausted; and local healthcare services provide insufficient palliative care. Trigger moments are not only crucial for assessing and treating the current problem but can also indicate that a patient is deteriorating. An emergency department visit is such a trigger.[53] The top five reasons patients in the palliative phase visited the emergency department in Ontario in 2002-2005 were abdominal pain, lung cancer, pneumonia, dyspnoea and malaise and fatigue.[54] Grudzen et al.'s randomised controlled trial in 136 patients with advanced cancer who visited the emergency department studied the effect of emergency department-triggered palliative care. They found that patients who had received palliative care triggered by the visit had a better quality of life than patients who received standard care.[55]

3.3 Estimation of the patient's functioning and other clinical characteristics

To support healthcare professionals in estimating the life expectancy of their patients, it may be helpful to know which factors predict approaching death. Predictors of approaching death can function as triggers for initiating a palliative care approach.[56] A predictor that is easy to use is poor performance status (measured using, for example, the European Cooperative Oncology Group (ECOG) Performance Status, World Health Organisation (WHO) Performance status or Karnofsky Performance Score), which is predictive of approaching death in patients with terminal cancer.[57-60] The ECOG performance status, depicted below, is scored by the patient's clinician with a score from 0 to 5 and is mostly used by clinicians to decide if the patient is fit enough to undergo systemic treatment. Poor performance is usually defined as an ECOG performance score of 3 and 4.[61]

Table 1. ECOG performance status[60]

Grade	ECOG performance status
0	Fully active, able to carry on all pre-disease performance without restriction
1	Restricted in physically strenuous activity but ambulatory and able to carry out work of a light or sedentary nature, e.g., light housework, office work
2	Ambulatory and capable of all selfcare but unable to carry out any work activities; up and about more than 50% of waking hours
3	Capable of only limited selfcare; confined to bed or chair more than 50% of waking hours
4	Completely disabled; cannot carry on any selfcare; totally confined to bed or chair
5	Dead

Apart from poor performance status, the occurrence or worsening of a number of symptoms in the palliative phase can be predictors for approaching death: anorexia, weight loss, dyspnoea, confusion and cognitive decline.[62-64] Prognostic models are more complex and including several clinical predictors can help clinicians assess whether patients have a short estimated life expectancy.[56, 65] Examples are the Palliative Performance Scale, Palliative Prognostic Index, Palliative Prognostic Score, Glasgow Prognostic Score and Chuang Prognostic Scale.[66-70] Most of the aforementioned prognostic models include many predictors of approaching death, which may be unpractical in daily practice.

Using predictors or prognostic models for approaching death to identify patients with palliative care needs can be helpful near the end of life to urgently arrange appropriate care. However, approaching death usually means death within three months. Predictors for approaching death are therefore less helpful in early identifying palliative care needs, because the opportunity to timely prepare patient and family for the end of life is missed out.

3.4 Estimation of life expectancy

Estimating the life expectancy of patients can help clinicians to become aware of possible palliative care needs and to determine which treatments are appropriate.[62] Clinicians can ask themselves a temporal question: “How long will this patient live?”, which is answered with a number of time units (for example, 10 months). The temporal question is considered a simple way to formulate estimated survival. However, temporal predictions are often too optimistic and not very accurate.[71] A probabilistic question, “What is the chance that this patient survives the following hours, days, weeks, months, or year?”, is more accurate, but more difficult to interpret.[56, 72] Moreover, clinicians are hesitant to estimate the patient’s life expectancy, because it may feel definitive and as if one provides a guarantee.[56]

3.5 Use of the Surprise Question

The surprise question, “Would I be surprised if this patient dies within one year?”, is a tool to early identify patients who may benefit from palliative care.[73] If the answer to the surprise question is “No, I would not be surprised”, assessment of palliative care needs should be conducted. The surprise question is asked and answered by the clinician. The surprise question is not primarily meant to estimate survival within one year, but it combines a clinician-estimated probability of death during the following year to identify those who are currently in need of palliative care, with a gut feeling.[73-75] Time frames other than death within one year (e.g., 6 months, 3 months, 1 month, or 1 week) can be used to determine the urgency of palliative care and what care should be aimed at, for example, supportive care, hospice care or terminal care.[76] Systematic reviews and meta-analyses show that the surprise question has a c-statistic for one-year mortality ranging from 0.512 to 0.822 with an accuracy of 75%. However, the surprise question lacks sensitivity and positive predictive value (67% and 37%, respectively).[77, 78] The surprise question might perform better when predictors of approaching death are added.[78] No studies are conducted to test whether the surprise question adequately identifies patients with palliative care needs. Nonetheless, use of the surprise question is still recommended in clinical guidelines, such as the Netherlands Quality Framework for Palliative Care.[2]

3.6 Use of tools combining identification methods

The Netherlands Quality Framework for Palliative Care advocates that criteria for palliative care case finding should become part of the care process. These criteria include trigger moments, predictors for approaching death, and the surprise question.[2, 40] Several screening tools are developed that combine the aforementioned ways of identifying patients with palliative care needs. Most of these tools are tested in patients with cancer, but there are also tools for patients with heart failure, chronic obstructive pulmonary disease, and frailty. There are adjusted versions for various healthcare settings as well. Screening tools identifying patients with palliative care needs are the Supportive and Palliative Care Indicators Tool (SPICT), Necesidades Paliativas (NECPAL) identification tool, Golden Standards Framework—Proactive Identification Guidance (GSF-PIG), Radboud indicators for Palliative Care Needs (RADPAC), and a Centre to Advance Palliative Care's checklist.[49, 50, 79-81] A recent systematic review on palliative care needs screening tools in primary care also included the Palliative care: Learning to Identify in people with intellectual disabilities (PALLI) and the 'Rainoe tool'.[82] In the Netherlands, the SPICT and RADPAC are most frequently used, which both combine the surprise question, trigger moments and clinical indicators.[2] In a more recent version of the SPICT, the surprise question was removed because studies showed its test performance was limited in patients with diseases other than cancer.[77, 78]

4. ASSESSMENT OF PALLIATIVE CARE NEEDS OF PATIENTS AND THEIR FAMILY

After identification of patients and family with palliative care needs, discussions about their wishes regarding the last phase of life, and comprehensive assessments of the physical, psychological, social, and spiritual dimensions should take place across the illness trajectory.[2, 83] This section demonstrates the assessment of palliative care needs and information needs (4.1), and the importance of early discussion of the end-of-life preferences of patients and their family (4.2).

4.1 Assessment of palliative care needs

Assessment of patient-reported symptoms in palliative care is beneficial since it improves quality of life, reduces emergency department admissions, and may even improve one-year survival, as is shown in Basch et al.'s randomized controlled trial in 766 patients with advanced cancer.[84] Many tools have been developed to structure assessments of problems and symptoms in the four dimensions of palliative care: the physical, psychologic, social and existential.[83, 85, 86] Most multidimensional assessment tools are developed for assessments in patients with cancer.[86] The following paragraph focusses on the tools that are used most frequently in the Netherlands.

In 2018, IKNL published a selection of measurement instruments in palliative care that are validated in Dutch and validated for use in palliative care.[2, 87] These instruments are of multidimensional nature:

Table 2. List of multidimensional instruments for assessing palliative care needs, derived from the Dutch quality framework on palliative care.[2]

Instrument	**Target population**	**Aim**	**Dimensions addressed**			
			Physical	*Psychological*	*Social*	*Spiritual*
Lastmeter[88] *(Distress Barometer)*	Patients with cancer	Signalling experienced burden of disease	x	x	x	x
USD[89]	Patients in the palliative phase	Signalling and monitoring of symptoms	x	x		
CRQ[90]	Patients with chronic lung disease	Monitoring of quality of life	x	x		
CaReQoL CHF[91]	Patients with heart failure	Monitoring and targeted assessment of quality of life	x	x		
GFI[92]	Elderly	Targeted assessment of frailty in elderly during treatment decision-making	x	x	x	
G8[93]	Elderly patients with cancer	Targeted assessment of frailty in elderly during cancer treatment decision-making	x	x		

List of abbreviations: USD: Utrecht Symptom Diary; CRQ: Chronic Respiratory Questionnaire; CaReQoL CHF: Care Related Quality of life voor Chronisch Hartfalen; GFI: Groningen Frailty Indicator; G8: Geriatric Assessment 8.

The Edmonton Symptom Assessment System (ESAS), developed by Bruera et al. in 1991, was the first tool to use numeric rating scales (from 0, no complaints, to 10, worst complaints) to assess and monitor patient-reported symptom burden for symptoms that are common in the palliative phase: pain, tiredness, nausea, depression, anxiety, drowsiness, decreased appetite, poor sense of well-being, shortness of breath.[94] The ESAS has been widely studied since 1991: from the trajectories of symptom burden, to its role as a trigger in identifying palliative care needs and its integration into electronic patient files.[95] Symptom scores of ≥4 are considered clinically relevant, warranting more comprehensive assessment and treatment, and scores of ≥7 are considered as serious burden.[96] Several studies conclude that a difference of one point on the numeric rating scales is a clinically relevant change in symptom intensity.[97, 98]

The ESAS was translated into more than twenty languages, including Dutch.[89] The validated Dutch version, the Utrecht Symptom Diary (USD), includes numeric rating scales for common problems. Also, patients can fill out which complaint(s) or problem(s) should be addressed first. The USD addresses physical and psychological symptoms or problems. To also acquire an assessment of the social and spiritual dimensions, researchers of the Dutch academic hospice Demeter and the University of Humanistics developed the

USD – 4 dimensional (USD-4D).[99] The USD-4D is congruent with the Ars Moriendi model developed by Carlo Leget, which is depicted as a diamond existing of five continuums that represent aspects of dying.[100] The content of the USD-4D is validated from the perspective of patients.[99]

According to IKNL's selection in Table 2, only the Lastmeter would suffice in identifying patients who have palliative care needs in all four palliative care dimensions. The new USD-4D will probably be added to this list as it is content-validated and includes the four palliative care dimensions.[99]

4.2 Assessment of information needs

It is necessary to assess the needs of patients and family in order to support them. A study using the Dutch Potential problems and Needs for Palliative Care (PNPC) questionnaire found that patients indicate different items they experience as a problem and items they wanted professional attention for.[101] The authors concluded that problems are not the same as unmet palliative care needs. Assessment of palliative care needs of patients and their family should also include assessment of their information needs, and of how they cope with their prospects. Additionally, patients and their family need support in remembering what was explained during consultations.[102-106] While patients and their family have information needs about palliative care, they are often unaware of the questions they can ask during palliative care consultations.[106, 107] Lack of knowledge about palliative care and insight into their information needs impedes their sense of self-efficacy and may result in a sense of loss of control over their lives.[108, 109] For healthcare professionals, it is essential to communicate effectively to acquire insight in the palliative care and information needs.[110-112] Information-provision to patients with an advanced disease and their family stimulates self-management and supports coping with the disease now and in the future.[113] A study by Temel et al. in 2017 showed that end-of-life preferences were discussed more often in patients who received palliative care plus standard care, versus standard care alone. This implies that application of a palliative care approach encourages discussions about the needs, wishes and values of patients and their family.[114] During palliative care needs assessments, generalist palliative care healthcare professionals often do not inquire their patients thoroughly enough. They mostly focus on the physical dimension, and often do not assess information needs.[115, 116]

Question prompt lists are structured lists with sample questions patients and their family may ask during conversations with their clinician and to share information needs.[117] Patients and their family are asked to prepare their palliative care consultation by indicating which questions they would like to ask. Most question prompt lists are used in patients with (advanced) cancer.[118-130] Studies about these oncology question prompt lists have shown that patients find question prompt lists helpful, that they ask more questions, especially about prognosis or end-of-life issues, that they were more satisfied with the consultation, and that healthcare professionals provide more information.[117, 124]

Clayton et al. developed a question prompt list for use in palliative care. They asked input from clinicians, patients, and their family.[112] In their randomised controlled trial, they found that patients and family who had used the question prompt list asked twice as many questions compared to those who had not. They asked more questions about prognosis and end-of-life issues. Less information needs about the future were left unaddressed. On average, the consultations were 31 minutes longer when a question prompt list was used. There were no differences in satisfaction with care or anxiety scores between patients who did and did not use the question prompt list.[131] The question prompt list of Clayton et al. can be used by both patients and their family. Hebert et al. developed a question prompt list focused on family of patients in need of palliative care. They asked input from family and clinicians to compose the question prompt list. Their pilot study demonstrated that both family and clinicians found it useful in practice.[132]

In 2013, the hospital palliative care consultation team of Leiden University Medical Center constructed a conversation guide that combines the Utrecht Symptom Diary with an adapted Dutch version of the question prompt list by Clayton et al. This conversation guide is called Leiden Guide on Palliative care (LGP). The LGP is handed out to patients and their family as preparation for consultations with the palliative care consultant. The use of the LGP has not been evaluated before.

5. CONTEXT OF THIS THESIS

Since its start in 2011, the Center of Expertise in Palliative Care (CEPC) of Leiden University Medical Center hosts a specialist palliative care consultation team that holds the responsibilities of a specialist palliative care team as described by Henderson et al.[23, 133] The core activities of the CEPC are aimed at integration of care, education, and research; empowering generalist healthcare professionals; and supporting patients and their family. The palliative care consultation team uses the four-dimensional palliative care approach including the physical, psychologic, social, and existential dimensions in all their activities. The CEPC has formulated the following points of focus:

- Transmural and interdisciplinary collaboration between all care settings (home, hospice, nursing home and hospital)
- Timely identification of patients with palliative care needs
- Advance care planning
- Empowering patients and their family
- Two-track approach: the integration of a palliative care approach into standard care

6. AIMS AND OUTLINE OF THIS THESIS

The studies presented in this thesis reflect bottlenecks that were identified by our palliative care consultation team through their clinical experience since 2011. Additional bottlenecks were identified through quality-of-care evaluations and surveys that were held in Leiden University Medical Center to assess barriers and facilitators to hospital palliative care.[133] Important bottlenecks that were subject to research and are included in this thesis were:

- Palliative care education needs expressed by generalist clinicians
- Unnecessary and preventable healthcare transitions to the emergency department (ED)
- Patients and family being unaware of their palliative care and information needs

The aim of this thesis was to find opportunities to improve proactive palliative care by providing insight in:

- Current Dutch medical education;
- Timely identification of patients with palliative care needs; and
- Ways to support patients, their family, and clinicians to tailor conversations about palliative care.

The studies in this thesis included input from patients and their family, and from professionals from the field of education, clinical practice, and research.

The research objectives of the studies in this thesis were the following:

1. To assess the extent to which end-of-life care is taught at medical schools in the Netherlands and to find opportunities to improve Dutch medical curricula.
2. To explore palliative care needs and the extent of proactive care in patients with advanced cancer who visited the ED in the last three months of their lives.
3. To describe the end-of-life trajectory and quality of care of patients with a haematological malignancy who visited the ED in the last three months of their lives, compared to patients with advanced cancer.
4. To evaluate the performance of the surprise question to identify palliative care needs in patients with advanced cancer visiting the ED.
5. To explore the association between symptom burden and information needs of patients referred to a hospital palliative care consultation team using the Leiden Guide on Palliative care (LGP).
6. To evaluate and further develop the question prompt list of the LGP to prepare the question prompt list for use by generalist palliative care clinicians.

Chapter 2 (aim 1) discusses the integration of end-of-life care in Dutch medical curricula. End-of-life care was chosen instead of palliative care because sufficient end-of-life care education is vital to improve palliative care education. Based on literature review, a checklist was made comprising of elements that are essential in undergraduate medical education. Using this checklist, we assessed the National Blueprint on Medical Education, the bachelor, and master curricula of all eight medical faculties of the Netherlands and their elective courses in 2016. In **Chapter 3** (aim 2), disease and visit characteristics are described of 420 patients with advanced cancer visiting the ED between 2011 and 2013. Possible predictors for approaching death were analysed to support screening for urgent palliative care needs at the ED. **Chapter 4** (aim 3) presents the end-of-life trajectories of 78 patients with a haematological malignancy visiting the ED in the last 3 months of life. The quality indicators of Earle et al. were used to describe the quality of end-of-life care provided to patients with a haematological malignancy.[13] A comparison was made with 420 patients with a solid tumour. The test characteristics of the surprise question are studied in **Chapter 5** (aim 4). An observational prospective cohort study was conducted in 245 patients with advanced cancer who visited the ED in 2013 to 2014. Other predictors for approaching death were tested, and we evaluated whether addition of these predictors improved the test characteristics of the Surprise Question. **Chapter 6** (aim 5) provides an overview of the symptom burden and information needs of 321 patients referred to a hospital palliative care consultation team, using data from Leiden Guides on Palliative Care collected between 2013 and 2018. The association between symptom burden and information needs was studied. The evaluation and further development of the Leiden Guide on Palliative Care was carried out from 2017 to 2019 and is described in **Chapter 7** (aim 6). Qualitative methods including thematic analysis of 35 semi-structured interviews and open coding of 33 recorded consultations were used to acquire input from patients, their family, and clinicians. **Chapter 8** concludes this thesis with a general discussion of how our findings can improve proactive palliative care, and provides recommendations for future research, education, clinical practice, and policy.

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CHAPTER 2

End-of-life care in the Dutch medical curricula

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ABSTRACT

Introduction

Future doctors must be trained in giving appropriate care to terminal patients. In several countries, medical curricula have been reviewed for the attention devoted to end-of-life care (ELC). In the Netherlands, no formal review had been performed. Therefore, the aim of this study was to provide an overview of the Dutch medical curricula regarding ELC.

Methods

We formed a checklist based on international standards consisting of five domains of ELC education that are considered essential. Firstly, we studied the Dutch national blueprint on medical education. Secondly, using a questionnaire based on the checklist we studied the curricula of the eight medical faculties. A questionnaire was sent to all Dutch medical faculties to study the compulsory courses of the curricula. To assess the elective courses, we consulted the study guides.

Results

The national blueprint included four of the five domains of ELC. None of the eight medical faculties taught all domains specifically on ELC; they were taught within other courses. Most attention was given to the domains on psychological, sociological, cultural, and spiritual aspects; communication and conversational techniques; and juridical and ethical aspects. One faculty taught an elective course that included all essential aspects of the international standards.

Discussion

Our study shows that ELC is currently insufficiently mentioned in the national blueprint and that none of the faculties fully integrated ELC as a part of their compulsory medical curricula. To improve ELC education, we recommend the Dutch Federation of University Medical Centres to add the five ELC domains to the national blueprint and we recommend the medical faculties to review their curricula and offer a separate and compulsory course on ELC to prepare their students for their future medical practice.

INTRODUCTION

More people are living to ever increasing ages which has resulted in a large part of healthcare being devoted to chronic age-related diseases. Additionally, numerous diseases that used to be fatal have been turned into more chronic diseases by improved treatments. Medical and technical possibilities at the end of life have also increased substantially. All these developments have led to an increasing number of people needing complex end-of life care (ELC). To complicate matters, people also increasingly believe in the manipulability of the human life course and wish to be actively involved in decision-making. For the work of medical doctors, good ELC, as part of palliative care[1], is more important than ever before. At the moment, however, ELC is not yet optimal. For example, on the ICU, a third of the doctors questioned thought the care for at least one patient at that moment was disproportional, of which most care was considered futile and potentially harmful.[2] Moreover, doctors often offer palliative care too late and end-of-life discussions are not carried out frequently enough and often too late.[3-5] These factors influence the quality of life of terminal patients in a negative way.[6,7] To improve the quality of life at the end of life doctors should be properly trained in ELC as a part of palliative care. Research has shown that students should be taught about ELC especially in the preclinical years of medical education, since these years are the most important for the development of basic skills, attitudes, and knowledge for general medical practice. Besides, training in ELC does not conflict with other medical educational agendas since the acquired skills are useful to every healthcare specialization.[8-10]

Worldwide, many studies have been performed to assess the attention to ELC in medical curricula. After having assessed the status quo of ELC in medical education, medical schools in several countries adapted their curricula to implement themes related to ELC, such as palliative care, hospice care and terminal care. In the United States, the first study that assessed the quality and quantity of ELC education was conducted in students and residents in 2003, concluding that fourth year medical students did not feel well-prepared to provide ELC and suggesting curricular changes and improvements in the medical working and educational sphere for students to learn how to provide good ELC.[11] In 2004, the same authors interviewed the deans of 51 medical schools in the US about ELC education in the curricula of their schools and concluded that most deans were willing to improve ELC education.[12] In Europe, the status of palliative care medical education in the undergraduate curricula of 43 countries was evaluated in 2015. Although palliative medicine was taught in a vast majority of European countries, there were substantial differences in the level of development of education about palliative medicine.[13] Several individual countries such as Switzerland, the United Kingdom and Germany studied their medical curricula and recommended curricular changes such as the addition of internships in hospices and more education about palliative care.[14-17] By contrast, little is known about the status of ELC in the Dutch medical curricula. In a report on appropriate care in the last phase of life, the Royal Dutch Association on the Advancement of Medicine (KNMG) stressed the importance of appropriate caregiving to terminally ill patients and of proper education about ELC.[18] However, no studies have been performed yet to determine to what extent ELC is taught in the Dutch medical curricula. Therefore, this study assesses ELC in the Dutch national blueprint (Raamplan Artsopleiding 2009)[19] and the Dutch medical curricula.

METHODS

To investigate to what extent ELC is currently taught at Dutch medical schools, we used the following definition of end-of-life, as described by the KNMG: ‘the phase of very old age, or the phase of a condition that will be life-threatening in the near future.’ Care for those who are at the end of life includes concepts such as appropriate care, curative and palliative care, and over- or under-treatment.[18]

To study the themes regarding ELC systematically, we designed a checklist. This checklist combined the criteria for essential elements in ELC education established by two international expert groups,[8,20] and consisted of five main domains and twenty-two subdomains of ELC education (see Tab. 1).

To assess the national blueprint and the medical curricula in the Netherlands, we took the same approach as a Dutch assessment of medical education on geriatrics:[21] we assessed the national level by studying the national blueprint and we assessed the faculty level by contacting the bachelor and master directors of medical curricula of the Dutch medical faculties.

Firstly, the national blueprint for higher medical education was studied using our checklist.[19] The national blueprint serves to secure that future doctors are trained in the basic competencies they need in their medical practice. This was done by two researchers (JdB and MV) independently. If they came to different assessments, their findings were discussed until agreement was reached.

Secondly, we assessed the curricula of the eight medical faculties by developing a questionnaire based on our checklist. The questionnaire studied the content and the didactic form of the current formal ELC education at the Dutch medical faculties. All eight medical schools in the Netherlands were approached: University of Groningen, University of Amsterdam, VU University Amsterdam, Leiden University, Erasmus University Rotterdam, Utrecht University, Maastricht University and Radboud University Nijmegen. To investigate the formal medical curricula, the coordinators of the bachelor and master programs of each medical faculty were invited to participate in the study.

Table 1. The five domains and 22 subdomains of essential ELC education composed of criteria formulated by Barnard et al.[7] and Emanuel et al.[17]

Domain 1: Psychological, sociological, cultural, and spiritual aspects	Suffering
	Loss
	Mourning
	Rituals and meaning at the end of life
Domain 2: Communication and conversational techniques	Listening to the impact of disease on the patient's life
	Explore hope, helplessness, and fear in depth
	Discuss loss and mourning
	Discuss spiritual considerations
	Discuss advance care planning
Domain 3: Pathophysiology and treatment of symptoms	Pain
	Dyspnoea
	Dehydration
	Depression
	Delirium
	Fear
Domain 4: Juridical and ethical aspects	Not starting/stopping treatment and euthanasia
	Dilemmas on the treatment of pain
	Non-abandonment of the patient
Domain 5: Self-reflection on personal and professional experiences with death and loss	Personal experience with death
	View on the hereafter
	Goals of medicine
	Role of the doctor and other health workers in ELC

They could either submit the questionnaire by email or were interviewed (telephone interviews) using the questionnaire, which was done in almost all cases. In addition, the elective courses of each medical faculty were studied using online course catalogues or by contacting coordinators of the elective programs when course catalogues were not available online.

The study was carried out in accordance with the Declaration of Helsinki, including, but not limited to, there being no potential harm to participants, that the anonymity of participants was guaranteed, and that informed consent of participants was obtained. The study was approved by the institutional scientific review board.

RESULTS

The national blueprint

The assessment of the national blueprint is described in Tab. 2. We found that four of the five domains were present in the national blueprint. The national blueprint did not mention the first domain on psychological, sociological, cultural, and spiritual aspects of death and dying. The fourth and fifth domain were only marginally mentioned in the light of other subjects in the national blueprint.

Table 2. The presence of the five domains of end-of-life care (ELC) in the Dutch national blueprint for medical education

	End terms national blueprint	
Domain 1: Psychological, sociological, cultural, and spiritual aspects of death and dying	-	
Domain 2: Communication and conversational techniques	6.2.2.4.	After the bad news conversation, the young doctor is able to guide and support the patient and his loved ones adequately.
	6.2.2.4.	To guide and support the chronically and the terminally ill in palliative care.
Domain 3: Pathophysiology and treatment of symptoms	7.2.4.5.	After the master program, the young doctor has knowledge about care for the terminally ill and the young doctor has knowledge about the dying process and about determining the cause of death.
	8.3.1.2.4.	After the bachelor program, the student has knowledge on the conception and development, growth, and sexual maturation, and ageing and dying of an organism.
	9.2.2.5.	After the master program, the young doctor has knowledge on and insight in the conception, development, growth, sex maturation, ageing and dying process of an organism.
	9.2.2.7.	After the master program, the young doctor has knowledge on and insight in pathophysiology of the dying process and death of an organism.
Domain 4: Juridical and ethical aspects	9.3.3.10.	After the master program, the young doctor has knowledge on and insight in the principles of medical ethics and can deal with dilemmas such as induced abortion or euthanasia.
Domain 5: Self-reflection on personal and professional experiences with death and loss	6.2.7.4.	After the master program, the young doctor should have the competence to reflect on his/her own performance in difficult or moving situations.
	6.2.7.4.	After the master program, the young doctor should have the competence to recognize his/her own feelings and norms and values in relation to existential questions on life, death, disease, and health.

The medical curricula

The questionnaire for the assessment of the curricula was completed by all eight Dutch medical faculties (see Supplement 1 for the respondents and their positions). In five of the eight participating faculties, both the bachelor and the master education directors participated. In the case of Maastricht University, data were collected via another curriculum expert with permission of the bachelor and master coordinators. Since the respondent of Radboud University Nijmegen was responsible for both the bachelor and the master curriculum, a distinction could not be made. Data of the master program of Erasmus University Rotterdam were not available due to time restraints of the responsible persons.

Tab. 3 shows the assessment of the medical faculties. We found that none of the medical curricula taught all subdomains specifically on ELC and that no faculty addressed all five ELC domains in a specific course in the compulsory curricula. The form of ELC education varied. Education was considered specific on ELC if education was dedicated to the topic, for instance working groups on breaking bad news. Our study shows that 6 of the 8 faculties offered ELC-specific education for at least 1 subject. Of the 8 faculties, 2 did not offer ELC-specific education. The first domain was taught best, being offered specifically on ELC in 6 of the 8 faculties. The fifth domain received the least attention in Dutch medical education: in 4 of the 8 faculties, as ELC-specific education was only offered in 2 of the 4 subdomains.

Most ELC-specific education was taught in an interactive way; only 2 faculties used passive educational forms (i.e., lectures) to educate their students about 4 subjects regarding ELC.

In all domains, ELC-related subjects were interwoven in lectures, working groups, discussion groups or practical training on more general topics; this education is not specific on ELC, but ELC does have a place in this education. For example, *treatment options for pain in ELC* was often part of a lecture on pain treatments in general. The University Medical Center Groningen facilitates education driven by students' preferences and therefore does not offer ELC-specific education in the compulsory curriculum.

We also studied the elective curricula of the eight faculties. One faculty, Radboud University Nijmegen, offered the elective course *Coping with death* that covered all five domains. Three of the eight faculties taught in total five elective courses in which ELC plays a role: *Pain and pain treatment*; *Palliative care*; *Oncology*; *Paediatric oncology*; *Intensive care medicine*; and *Ethics in health care*.

Table 3. Education on end-of-life care in the Dutch medical curricula

	1		2		3		4		5		6		7		8
	B	**M**	**B**	**M**	**B**	**M**	**B**	**M**	**B**	**M**	**B**	**M**	**B**	**M**	**B&M**
Domain 1: Psychological, sociological, cultural, and spiritual aspects															
Suffering	○	○	●	○	–	○	●	–	○	●	–	●	●	*n*/a	●
Loss	○	–	○	○	–	○	●	–	○	○	–	–	–	"	●
Mourning	○	–	○	○	–	○	●	–	○	○	–	–	+	"	●
Rituals and meaning at the end of life	–	–	●	●	–	○	–	–	–	–	●	–	+	"	–
Domain 2: Communication and conversational techniques															
Listening to the impact of disease on the patient's life	○	○	○	○	○	○	●	○	○	○	●	●		"	●
Explore hope, helplessness, and fear in depth	○	○	○	○	○	–	–	–	–	●	–	●	–	"	●
Discuss loss and mourning	○	–	○	○	○	–	●	–	–	○	●	–	–	"	●
Discuss spiritual considerations	–	–	○	–	–	–	–	–	–	–	–	●	–	"	●
Discuss advanced care planning	–	○	○	○	○	–	●	–	●	●	–	●	–	"	○
Domain 3: Pathophysiology and treatment of symptoms															
Pain	○	○	●	○	○	○	●	●	●	○	●	●	○	"	●
Dyspnoea	○	○	○	○	○	○	–	○	○	○	○	●	○	"	●
Dehydration	○	○	○	○	–	○	○	○	○	–	○	●	○	"	●
Depression	–	○	○	○	○	○	–	○	●	–	●	●	○	"	○
Delirium	–	○	○	○	–	○	●	○	○	○	○	–	○	"	○
Fear	–	○	○	○	○	○	–	○	●	–	●	–	○	"	○
Domain 4: Juridical and ethical aspects															
Not starting/stopping treatment and euthanasia	○	○	●	●	○	○	●	○	●	○	●	●	●	"	–
Dilemmas on the treatment of pain	○	○	○	●	–	○	●	●	+	○	–	–	+	"	–
Non-abandonment of the patient	–	○	○	○	–	–	●	○	○	–	○	○	○	"	–
Domain 5: Self-reflection on personal and professional experiences with death and loss															
Personal experience with death	–	–	●	●	–	○	●	–	–	●	●	–	–	"	–
View on the hereafter	–	–	○	–	–	–	–	–	–	–	–	–	–	"	–
Goals of medicine	○	○	○	○	○	○	–	–	○	○	○	–	○	"	○
Role of doctors and other health workers in ELC	–	○	○	○	–	○	●	–	○	○	–	●	–	"	○

● Interactive, ELC-specific education; working group, discussion group, practical sessions, + Passive, ELC-specific education; lectures, ○ Non-ELC-specific education; interwoven in courses, – No ELC-education, n/a Not available, 1 University Medical Center Utrecht, 2 VU University Medical Center, 3 University Medical Center Groningen, 4 Leiden University Medical Center, 5 Amsterdam University Medical Center, 6 Maastricht University Medical Center, 7 Erasmus University Medical Center, 8 St. Radboud University Medical Center, B bachelor, M master

DISCUSSION

The five domains of ELC that are considered essential are currently not taught to medical students of all faculties. This is an important observation when taking into account the growing attention to the patients' quality of life at the end of life which demands proper training in ELC for all medical doctors.

The national blueprint

We found that the national blueprint contained only four of the five domains of ELC education that are considered essential skills, knowledge, and attitudes for young medical doctors. Furthermore, the domains are described in a very general way and can be easily overlooked in the national blueprint. Lack of national guidelines for ELC and palliative care has led to legal implementation of palliative medicine education in Germany and Switzerland and the national curricula on palliative care in Australia (the Palliative Care Curriculum for Undergraduates Initiative) and Canada.[22,23]

The new CanMeds Model of 2015, which serves as an international guideline for medical education around the world, holds several improvements in the light of ELC education. Most importantly, it now explicitly describes the key competence to discuss cultural matters, which includes beliefs about the end-of-life. However, the new CanMeds model still lacks several domains of the international checklist, and we therefore recommend addition of all ELC domains.

The medical curricula

The most prominent finding of the curricular assessment was that none of the eight faculties offered complete ELC education. This indicates that ELC education is not yet well-developed in the compulsory medical curricula in the Netherlands. These results are consistent with existing literature from other countries. One study, investigating the extent to which palliative medicine was taught in the Swiss medical curricula, showed that not all domains were covered in all curricula of the different medical faculties.[14] Furthermore, a series of studies measured the status of palliative care education in the UK, indicating that at first, in 1983, only 4 of the 24 medical schools taught (informal) education dedicated to palliative care.[24] These findings led to opportunities to alter and test the medical curricula regarding ELC education, which is done regularly in the UK and Germany.[16,25,26]

Currently, the attention of the ELC domains in the curricula varied. This is in line with a study on palliative care in medical education at a European level: in 27% of the countries, the faculties could determine whether and how they teach palliative care and consequentially the quality of palliative care education differed within these countries.[13]

Only one faculty (Radboud University Nijmegen) offered an elective course that paid attention to all the domains. Here, we see opportunities to develop and share educational programs on ELC to improve the elective program.

There are numerous possible explanations for the shortage of attention to ELC in the medical curricula. Firstly, there is still a taboo on talking about death and dying.[5] Furthermore, since many practising physicians were never formally trained in ELC themselves, this makes it difficult to pass this knowledge on to future generations. Moreover, as mentioned by two respondents who acknowledged the importance of ELC in medical education, other subjects were prioritized over ELC because ELC was not described explicitly in the national blueprint. These and other reasons for incomplete ELC education are described extensively in the report on Appropriate care in the last phase of life, published by the Royal Dutch Association on the Advancement of Medicine.[18]

This overview of current ELC education has several implications for practice. Firstly, since the national blueprint does not cover all the aspects of ELC education that are considered essential knowledge by international standards, we recommend adding all five domains and their subdomains to the national blueprint. The absence of the multi-dimensional approach of ELC in the national blueprint results in deprioritizing of ELC at the faculty level. Secondly, this study suggests that exchange of information and knowledge on ELC education can improve Dutch medical education on ELC. For example, Radboud University Nijmegen developed an elective course on ELC that included all five domains of our checklist, and this course could therefore serve as a model for other faculties. Thirdly, this study can be used to compare curricula with international medical education standards and to identify room for improvement. Fourthly, this study can be used as a baseline measurement for testing future curricular changes. And lastly, the established questionnaire for the different faculties can be used as a measurement tool for further research on ELC education in the future.

Limitations

There are four possible limitations of this study. Firstly, the data of the master medicine of the Erasmus University Rotterdam were not available because of time restraints of the responsible persons. Therefore, our overview of ELC in Dutch medical education is not fully complete. However, since otherwise all the data were collected, this study still provides a reliable overview of the medical curricula and indicates many possibilities for improvement of medical education dedicated to ELC. Secondly, since ELC was mainly integrated into other compulsory courses, the education directors reported that it was difficult to give a precise indication of the presence and time spent on the domains on ELC. Therefore, they may have given a more positive or negative view of their curricula, which would make our assessment an overly optimistic or overly pessimistic view of the current situation of ELC education. Thirdly, since the curricula are always in development, this review provides a cross-sectional view that possibly contains parts of old and new curricula. Fourthly, some respondents reported that the questionnaire was difficult to fill in, because ELC education was often part of education about other topics. Therefore, we opted to discuss the results with the respondents using telephone interviews, which was done in almost all cases.

Although this research shows the current situation of ELC education in the Netherlands regarding the national blueprint and the curricula, no studies have been performed to assess the individual level of the skills and knowledge of the students. Further research should therefore focus on the personal experience and knowledge regarding ELC of the medical students themselves. Other international studies also studied to what extent future doctors feel prepared to provide ELC. This will give further indications on how to better prepare medical students for their future medical practice. At the time of writing this article, the PASEMECO project of Maastricht University is assessing students' skills and knowledge regarding ELC and developing and implementing e-learning on palliative care in the Dutch medical curricula.

CONCLUSION

Our study shows that ELC is sparsely described in the Dutch blueprint for medical education: it is not explicitly mentioned as a compulsory subject and not all domains that are considered essential knowledge and skills by the international standards are represented in the national blueprint. This has consequences for the planning and execution of the medical curricula at the faculty level. First of all, ELC was part of the formal curricula, but none of the faculties taught all the subjects that were considered a necessary basis for ELC practice. Moreover, ELC was not offered as an individual course in any of the Dutch bachelor and master medical curricula. Secondly, none of the medical faculties taught the five domains on ELC and met international criteria. To improve ELC education, we recommend addition of all the ELC domains that are internationally accepted to the national blueprint. Besides, we recommend medical faculties to offer a separate compulsory course on ELC to educate and prepare their future doctors properly, so that people in an ageing world can rely on young medical doctors who feel ready and well-informed when providing appropriate ELC.

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Conflict of interest

J. de Bruin, M.J. Verhoef, J.P.J. Slaets and D. van Bodegom declare that they have no competing interests.

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SUPPLEMENTARY MATERIALS

Supplement 1

Table 1. Characteristics of the respondents on end-of-life care in the Dutch medical curricula

Medical faculties	Respondents
UMCU	Director bachelor and master medicine
VUMC	Director bachelor medicine Director master medicine
UMCG	Director bachelor medicine Director master medicine
LUMC	Head of the Centre of Expertise Palliative Care + Coordinator Course Last Phase of Life Director master medicine
AMC	Director bachelor medicine Director master medicine + Coordinators Course Family Medicine and Course Medical Professional trainer
Erasmus MC	Interim Director bachelor medicine
MUMC	Researcher of the PASEMECO project (with consent of the bachelor and master coordinators)
RadboudUMC	Professor of Pain and Palliative Care

Abbreviations: UMCU: University Medical Center Utrecht; VUMC: Vrije Universiteit Medisch Centrum Amsterdam; UMCG: University Medical Center Groningen; LUMC: Leiden University Medical Center; AMC: Academic Medical Center (Amsterdam); Radboud UMC: Radboud University Medical Center (Nijmegen); Erasmus MC: Erasmus Medical Center (Rotterdam); MUMC: Maastricht University Medical Center.

CHAPTER 3

Palliative care needs of advanced cancer patients in the emergency department at the end of life: an observational cohort study

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ABSTRACT

Purpose

Patients with advanced cancer commonly visit the Emergency department (ED) during the last three months of life. Identification of these patients and their palliative care needs helps initiating appropriate care according to patients' wishes. Our objective was to provide insight into ED visits of advanced cancer patients at the end of life.

Methods

Adult palliative patients with solid tumours who died <3 months after their ED-visit were included (2011-2014). Patients, ED-visits, and follow-up were described. Factors associated with approaching death were assessed using Cox proportional hazards models.

Results

420 patients were included, 54.5% was male, median age 63 years. 54.6% was on systemic anti-cancer treatments and 10.5% received home care ≥1 per day. ED-visits were initiated by patients and family in 34.0% and 51.9% occurred during out-of-office hours. Dyspnoea (21.0%) or pain (18.6%) were most reported symptoms. Before the ED-visit, limitations on life-sustaining treatments were discussed in 33.8%, during or after the ED-visit in 70.7%. Median stay at the ED was 3:29h (range 00:12-18:01h), 319 (76.0%) were hospitalized. Median survival was 18 days (IQ-range 7-41). 104 (24.8%) died within 7 days after the ED-visit, of which 71.2% in-hospital. Factors associated with approaching death were lung cancer, neurologic deterioration, dyspnoea, hypercalcemia, and jaundice.

Conclusion

ED-visits of advanced cancer patients often lead to hospitalization and in-hospital deaths. Timely recognition of patients with limited life expectancies and urgent palliative care needs, and awareness among ED-staff of the potential of ED-initiated palliative care may improve the end-of-life trajectory of these patients.

BACKGROUND

Although cancer has become a chronic disease in many patients, still yearly 8.9 million patients die of widespread disease worldwide, which makes cancer a leading cause of death in developed countries.[1] To provide advanced cancer patients with a good quality at the end of life, integration of appropriate palliative care into standard care is essential.[2] Palliative care is driven by patients' care needs and wishes and must be offered while the illness is not yet life-threatening.[2] One important aspect of a good quality of end of life denoted by patients and their families is to be cared for at home and to die there.[3,4] Because identification of patients with limited life expectancies and urgent palliative care needs can be difficult, patients, family, and their health care professionals are often not timely prepared and educated about appropriate management of problems expected in the future given the disease trajectory. Advance care planning about patient's wishes and goals of care often take place too late. Consequently, many patients with advanced cancer and a limited life expectancy are admitted to an emergency department (ED), leading to hospital admissions and in-hospital deaths.[5-8] Commonly reported physical problems in patients with advanced cancer visiting the ED are pain, respiratory distress, gastro-intestinal problems, fatigue, disease progression, delirium and loss of consciousness.[5,8-11] One study found that the most common reason for ED visits in the last 2 weeks of life was not being able to cope with the situation at home.[5] Other reasons for patients and families to go to the ED are anxiety related to the disease; being defaulted to previously used health care services; feeling safe in and familiar with the hospital setting; and difficulties accessing community health care services, especially when the complaints were urgent or occurred during out-of-office hours.[12,13] It is plausible that although patients consider ED visits as unwanted and as a 'last-resort' solution for relieve of their problems, their distress caused by their disease and care burden leads to these ED visits.[13] ED physicians perceive several barriers to provide appropriate palliative care: the ED is an uncomfortable setting for dying patients,[14] physicians work under time pressure which makes palliative patients a low priority,[15] they lack confidence in their own palliative care skills,[16] do not build a long-lasting relationship with palliative patients and are consequently not comfortable with discussing limitations on medical treatments.[15,17]

Identification of advanced cancer patients with palliative care needs and a short life expectancy at the ED can help to improve the quality of the end of life by arranging appropriate care. Prediction scores for short-term death in advanced oncology patients are present, but they are not validated for the ED and are mostly extensive assessment tools requiring patient information that is not always accessible in an emergency-setting.[18]

To gain more knowledge on the course of events leading to ED visits at the end of life, the objectives of this study were to provide insight into characteristics of advanced cancer patients visiting the ED, their palliative care needs, and the actions undertaken during these ED visits.

METHODS

Setting

This study was conducted at the Leiden University Medical Center (LUMC) in Leiden, the Netherlands. LUMC's ED is open 24 h a day, 7 days a week. On average, 80 patients are evaluated every day for various reasons, including non-oncological problems. Since 2011, a palliative care consultation team (PCCT) is available in the LUMC for consultation of palliative patients.

Patients

Adult patients were included who visited the ED between May 2011 and June 2014, were in the palliative phase of cancer at the moment of the ED visit and died within 3 months thereafter. Patients were in the palliative phase if curation was not possible or if anti-cancer treatment was not directed at curation. The time period of 3 months represents the group of patients in urgent need of appropriate palliative care and appropriate end-of-life choices. Also, for the Dutch medical insurance system, this time period depicts the possibility of full reimbursement of necessary palliative home care or transfer to a hospice. Patients diagnosed with a haematological malignancy were excluded. Only data of the last ED visit before death were included.

Data collection

Characteristics of the patients, referrals, and the ED visit, and follow-up data were retrospectively collected from the electronic patient records (EPRs). The palliative disease phase was assigned by the researcher based on the disease trajectories described by Lynn and Adamson, in which three palliative phase can be discerned corresponding to the disease status: disease-modifying phase, in which anti-cancer treatment is given aimed at life prolongation or symptom management; symptom management phase, in which treatment is directed to symptom relief; or terminal phase.[19] EPRs were searched for notes reporting contact with general practitioners (GPs); for PCCT-consultations 3 months before the ED visit; and for proactive symptom management plans in files or letters until 6 weeks before the ED visit. Performance was scored using the Eastern Cooperative Oncology Group (ECOG) scale and was documented by the admitting hospital physician or estimated by the researcher based on the patient's physical functioning documented in the EPR.[20] Limitations on life-sustaining treatments included do-not-resuscitate orders, ‘no ventilation’-orders and ‘no intensive care unit (ICU) admission’-orders. The time of arrival at the hospital was defined as within office hours for visits from Monday to Friday between 8 a.m. and 6 p.m. The main symptom was defined as the symptom that led to the ED-referral as described in the EPR by the attending physician. New symptoms were defined as main symptoms not mentioned in the EPR 3 months before the ED visit. Acute symptoms were main symptoms with an onset within 24 h before the ED visit. The clinical diagnosis was defined as the conclusion of the attending ED physician.

Statistics

Characteristics of patients, referral, and ED visit were analysed using descriptive statistics. Kaplan-Meier’s method was employed to estimate survival since the ED visit. The following factors associated with death were derived from literature search and clinical experience: primary lung tumour, ED-admissions for a new and acute problem, limitations on life-sustaining treatments before the ED visit, main symptom at the ED of neurologic deterioration, main symptom at the ED of dyspnoea, clinical diagnosis of bleeding, clinical diagnosis of cachexia, clinical diagnoses of hypercalcemia, and clinical diagnosis of jaundice. These factors were used in univariable and multivariable analyses by using a Cox proportional hazards regression. Predictors with a p value of <0.10 in univariable analysis were entered in multivariable analysis. Differences with a p value <0.05 were considered statistically significant. All analyses were conducted with SPSS 23.0 software.

RESULTS

Patient characteristics

Four hundred twenty patients were included, median age was 63 years, and 229 (54.5%) patients were male (Table 1). Tumours located in the digestive tract occurred most frequently (27.6%). Anti-cancer treatment was provided to 73.6% of the patients in the 3 months before the ED visit. Most patients (62.6%) were in the disease-modifying palliative phase, with average time from diagnosis of the palliative phase to ED visit of 6.2 months (range 0–13.7 months). Most patients (92.6%) lived at home or in a residential home before the ED visit. Home care was arranged for 21.9% of the patients, and 10.5% received home care at least once a day. An informal caregiver was available for 87.1% of the patients. The PCCT was consulted for 26 patients (6.2%) in the last 3 months before the visit to the ED. Proactive symptom management plans were documented for 12.1% of the patients 6 weeks before the ED visit. Limitations on life-sustaining treatments had been discussed in 37.6% of the patients, and limitations had been documented in 33.8%.

Referral characteristics

Patients or their caregivers took the initiative to visit the ED in 34.0% for a median of 2.0 symptoms (Table 2). ED visits occurred outside office hours in 51.9%. The main symptom was new in 52.1% and acute in 36.9% of the patients and both new and acute in 29.3%. Most frequently reported main symptoms or signs were dyspnoea (21.0%), pain (18.6%), and ascites (11.9%). A total of 62.8% had an ECOG performance score of 3–4 (known in 196 of 420 patients).

Table 1. 420 patients with advanced oncology visiting the emergency department

Patient characteristics	**n**	**(% of 420)**
Male	229	(54.5)
Age in years, median (range)	63	(22-92)
Primary tumour site		
Digestive tract	116	(27.6)
Lung	67	(16.0)
Gynaecologic	47	(11.2)
Urologic	45	(10.7)
Breast	37	(8.8)
Head and neck	32	(7.6)
Other[a]		
Time since palliative diagnosis		
< 3 months	143	(34.0)
3 months – 1 year	144	(34.3)
1 year – 4 years	98	(23.3)
> 4 years	30	(7.1)
Palliative disease phase		
Disease-modifying	263	(62.6)
Symptom-management	157	(37.4)
Treatment for primary tumour in the last 3 months		
Chemotherapy	168	(40.0)
Hormonal therapy	28	(6.7)
Targeted or immunotherapy	75	(17.9)
Radiotherapy	104	(24.8)
Surgery	31	(7.4)
Other[b]	7	(1.7)
None	111	(26.4)
Limitations on life-sustaining treatments		
Not discussed	262	(62.4)
Discussed, no limitations documented	16	(3.8)
Discussed, limitations documented[c]	142	(33.8)

Table 1. 420 patients with advanced oncology visiting the emergency department (continued)

Patient characteristics	**n**	**(% of 420)**
Current housing situation[d]		
At home or residential home	389	(92.6)
Nursing home	12	(2.9)
Hospice	5	(1.2)
Home care		
No	225	(53.6)
Yes, unknown frequency	39	(9.3)
<1x/day	9	(2.1)
≥1x/day	43	(10.5)
Informal caregiver available according to EPR	366	(87.1)
PCCT consulted during the last 3 months	26	(6.2)
Proactive symptom-management plans		
In EPR, 6 weeks before the ED-visit	51	(12.1)
In a letter to the GP, 6 weeks before the ED-visit	30	(7.1)
Discussion with patient mentioned in EPR 6 weeks before the ED-visit	46	(11.0)

List of abbreviations: PCCT = palliative care consultation team; EPR = electronic patient record; ED = emergency department; GP = general practitioner
[a] Other: other most common primary tumour sites were unknown primaries; skin tumours; sarcomas; and nasal cavity and middle ear. [b] Other: nuclear therapy (1%), haemo- or peritoneal dialysis (0.2%), organ transplantation (0.2%), stem cell transplantation (0.2%). [c] Documented limitations were: no resuscitation: 62 (14.8%); no resuscitation, no ventilation: 11 (2.6%); no resuscitation, no ventilation, no admission to the intensive care unit: 68 (16.2%); refrain from any intervention: 1 (0.2%). [d] Current living situation was not known for 14 patients (3.3%).

Visit characteristics

At the ED, imaging and blood tests were performed in 63.3% and 83.3% of the patients, respectively (Table 3). Diagnoses most frequently reported by the attending physician were infection or fever (20.5%), bronchopulmonary insufficiency (12.9%), and renal insufficiency or hydronephrosis (11.2%). Patients spent a median time at the ED equal to 3:29 h (range 00:12–18:01). During or after the ED visit, limitations on life-sustaining treatments were discussed with 73.1% of the patients and 70.7% had limitations documented in the EPR. After the ED visit, 76.0% of the patients were hospitalized. Patients' median survival from the ED visit was 18 days; 104 patients (24.8%) died within 1 week. Of the 104 patients who died within 1 week, 74 patients (71.2%) died in the hospital and death within 1 week was associated to in-hospital death ($p < 0.0001$, HR 8.49). In total, 39.3% of the patients died at home, 29.5% in a hospital (i.e., in the clinic, intensive care unit or another hospital) and 11.0% died in a hospice. In-hospital death occurred less frequently in patients with a proactive symptom management plan sent to their GP compared to patients without (26.9% and 38.5%, respectively, $p = 0.03$). In-hospital death was not related to limitations on life-sustaining treatments, the referrer, or the number of previous admissions.

Table 2. Referral of patients with advanced oncology to the emergency department

Referral characteristics	n	(% of 420)
Referrer		
GP or nursing home physician	150	(35.7)
GP out-of-office service	21	(5.0)
Medical specialist	100	(23.8)
Patient or informal caregiver	143	(34.0)
Referral outside office hours	218	(51.9)
Referral for		
a new problem[a]	219	(52.1)
an acute problem[b]	155	(36.9)
a new and acute problem	123	(29.3)
Number of symptoms, median (range)	2.0	(0-7)
Main symptom or sign for referral		
Dyspnoea	88	(21.0)
Pain	78	(18.6)
Ascites	50	(11.9)
Nausea or vomiting	39	(9.3)
Fever	38	(9.0)
Neurologic deterioration[c]	33	(7.9)
Bleeding	20	(4.8)
Weakness or loss of strength	19	(4.5)
Obstipation or diarrhoea	16	(3.8)
Difficulty swallowing or passage problems	9	(2.1)
Oedema	8	(1.9)
Seizure	8	(1.9)
Fatigue	8	(1.9)
ECOG performance score		
0	4	(1.0)
1	26	(6.2)
2	43	(10.2)
3	89	(21.2)
4	34	(8.1)
Unknown	224	(53.3)

List of abbreviations: GP = general practitioner; ECOG = Eastern Cooperative Oncology Group

[a] New problem: not reported in the patient records in the last 3 months

[b] Acute problem: originated within the last 24 hours

[c] Neurologic deterioration: confusion, drowsiness, decreased consciousness

Table 3. Characteristics of emergency department-visit and follow-up

Visit- and follow-up characteristics	**n**	**(% of 420)**
Diagnostic imaging	266	(63.3)
Laboratory tests performed	350	(83.3)
Clinical diagnosis		
Infection or fever	86	(20.5)
Bronchopulmonary insufficiency	54	(12.9)
Renal insufficiency or hydronephrosis	47	(11.2)
Cachexia	40	(9.5)
Ascites	34	(8.1)
Pleural effusion	31	(7.4)
Bleeding	30	(7.1)
Jaundice	23	(5.5)
Hypercalcemia	20	(4.8)
Ileus or passage disturbances	18	(4.3)
Neuropathy or plexopathy	17	(4.0)
Seizure	13	(3.1)
Urine retention	13	(3.1)
Fracture	10	(2.4)
Coma	8	(1.9)
Pulmonary embolism	8	(1.9)
Deep venous thrombosis	7	(1.7)
Delirium	6	(1.4)
Spinal cord compression	5	(1.2)
Any treatment initiated at ED	230	(54.8)
Time spent at ED, median (range)	03:29	(00:12-18:01)
Limitations on life-sustaining treatments[a]		
Discussed, none documented	10	(2.4)
Discussed and documented	297	(70.7)
Not discussed	113	(26.9)
Hospitalization after ED-visit	319	(76.0)
Survival after ED-visit in days, median (95% C.I.)	18	(15-21)
Death within 7 days after ED-visit	104	(24.8)
Death within 14 days after ED-visit	170	(40.5)
Death within 30 days after ED-visit	274	(65.2)
Death within 60 days after ED-visit	370	(88.1)
Place of death		
Hospital[b]	124	(29.5)
Home or residential home	165	(39.3)
Hospice	46	(11.0)
Nursing home	4	(1.0)
Unknown	81	(19.3)

List of abbreviations: ED = emergency department; IQ range = interquartile range; ICU = intensive care unit
[a] during visit/after discharge. [b] 1 patient died at the ED (0.2%), 113 at a hospital ward (26.9%) and 10 at the ICU (2.4%).

Factors associated with approaching death

Independent risk factors for early death were primary lung tumour (HR 1.69, 95% CI 1.29–2.21, p <0.0001), referral for neurological deterioration (HR 2.01, 95% CI 1.38–2.92, p <0.0001) or dyspnoea (HR 1.57, 95% CI 1.23–2.00) and hypercalcemia (HR 1.92, 95% CI 1.21–3.03, p = 0.005) or jaundice (HR 2.11, 95% CI 1.37–3.26, p = 0.001) (Table 4).

Table 4. Risk factors for death after ED-visit

	Univariable analysis			**Multivariable analysis**		
Predictors	**H.R.**	**95% C.I.**	**P-value**	**H.R.**	**95% C.I.**	**P-value**
Primary lung tumour	1.67	1.28-2.18	<0.0001	1.69	1.29-2.21	<0.0001
ED-admission for new and acute problem	0.98	0.79-1.20	0.81			
Limitations on LSTs before ED-visit	1.26	1.02-1.54	0.029			NS
Main symptom at the ED						
Neurologic deterioration	1.85	1.29-2.66	0.001	2.01	1.38-2.92	<0.0001
Dyspnoea	1.48	1.17-1.88	0.001	1.57	1.23-2.00	<0.0001
Clinical diagnosis						
Bleeding	1.37	0.95-1.99	0.096			NS
Cachexia	1.43	1.03-1.98	0.034			NS
Hypercalcemia	1.80	1.14-2.83	0.011	1.92	1.21-3.03	0.005
Jaundice	2.21	1.44-3.39	<0.0001	2.11	1.37-3.26	0.001

List of abbreviations: H.R. = hazard ratio; C.I. = confidence interval; LSTs = life-sustaining treatments; ED = emergency department

DISCUSSION

This study provides a detailed description of patients with advanced cancer who visited the emergency department (ED) during the last 3 months of their lives and of the actions undertaken during these ED visits. In most patients, care seemed to focus on disease modification; many patients still received anticancer treatments, and few had proactive symptom management plans in case of progressive symptoms or limitations on life-sustaining treatments documented in their patient records. The ED visit triggered revision of limitations of life-sustaining treatments in the majority of patients. Following their ED visit, 76.0% was hospitalized in poor clinical condition and 29.5% died in the hospital; of those who died within 7 days, 71.2% died in-hospital. Factors associated with approaching death were found to aid identifying those patients with urgent palliative care needs at ED entry, in order to make appropriate decisions concerning their treatment and care trajectories.

ED staff, patients and their caregivers consider the ED setting an uncomfortable situation for patients at risk of approaching death.[13] Besides the hectic and noisy environment of the ED, there is little space for family members to stay with their sick relatives and to conduct end-of-life discussions. Palliative patients often have a lower priority than patients with acute life-threatening illnesses and therefore spend a lot of time waiting at the ED.[15] The overwhelming environment of the ED and uncertainty about the situation increases psychological distress and anxiety in patients and their caregivers.[21] For ED physicians, an important reason that makes it difficult to provide optimal care to palliative patients is that they have no long-lasting relationships.[13,22] Moreover, they are not trained to provide adequate symptom management for and to discuss end-of-life decisions.[13,21,22] Notwithstanding, ED physicians are willing to provide palliative care and indicated that in order to enhance a 'good death', attention should be directed to the care needs and wishes of patients in the palliative phase visiting the ED.[23,24] In our study, patients were exposed to many diagnostic tests (83% underwent blood tests, 63% diagnostic imaging) and stayed at the ED for 3.5 h on average, which was followed by hospitalization in over 75%. Since most patients prefer to spend the end of their life at home, these outcomes are undesirable.[3]

Few patients in our study had limitations on life-sustaining treatments documented, suggesting that palliative care needs and approaching death had not yet been discussed. Patients and caregivers who are unprepared for or unaware of the problems and symptoms that may occur at the end of life are more likely to visit the ED at the end of life,[15,25] especially during out-of-office hours.[8,13,26] This is supported by our results: 34% of the patients referred themselves to the ED and 52% of the ED visits occurred out-of-office hours. Several studies reported that the majority of the ED visits are undesirable and avoidable, especially those by patients with a very short survival.[5,26,27] End-of-life discussions have shown to have the potential to prevent ED visits in the last month of life in patients with ovarian cancer and stage IV lung and colorectal cancer.[28,29] Community-based palliative care effectively reduced the number of ED visits in the last phase of life in advanced cancer patients[30] and in the general patient population.[31,32] Furthermore, meta-analysis of numerous randomized clinical trials proved that integration of palliative care early in the disease trajectory improves health-related quality of life and symptom intensity in patients with advanced cancer.[33] Advance care planning and out-patient symptom management may help patients and their caregivers to prepare for the end-of-life trajectory and to avoid unnecessary ED visits by supporting coping with deteriorating health.[21,34] Although palliative care is often perceived as end-of-life care, palliative care can be provided concurrently with standard care.[35] Hence, timely initiation of palliative care is possible and helps to avoid unnecessary ED visits and can improve quality of life in the end-of-life phase.

Although early palliative care can avoid part of the ED visits at the end of life, there will still be patients visiting the ED for symptoms that are distressing and unmanageable at home. Additionally, patients may visit the ED when community palliative care services are not available, e.g., outside office hours.[15,21] ED visits can be an opportunity to recognize high symptom burden and acute deterioration, which should trigger initiation of appropriate palliative care. This is also known as ED-initiated palliative care.[36,37] Grudzen et al. conducted a randomized clinical trial in 2016 on palliative care consultations initiated at the ED in patients with advanced cancer and found that it significantly improved their quality of life.[37] Examples of ED-initiated palliative care are, among others, consultations by a specialized in-hospital team, community-based care by a homecare team or hospice team, telephone-based interventions, or admissions to a hospice or a palliative care unit.[33] Our finding that physicians documented more limitations on LSTs after the ED visit might indicate that they were well aware of changes in disease trajectories, creating an opportunity for effective ED-initiated palliative care. To facilitate cooperation with palliative care services, both at home and in the hospital, it is recommended to have a checklist with standardized criteria[38] for referral with contact details of the palliative care services easily available at the ED. An international consensus panel of 60 experts on palliative cancer care formulated 11 criteria for referral to specialized palliative care: nine needs-based criteria (severe physical symptoms, severe emotional symptoms, request for hastened death, spiritual or existential crisis, need for assistance with decision-making or care planning, referral on patient's request, delirium, brain or leptomeningeal metastases, spinal cord compression or cauda equine) and two time-based criteria (within 3 months of diagnosis of advanced cancer or incurable cancer for patients with a median survival of 1 year of less, diagnosis of advanced cancer with progressive disease despite second-line systemic therapy).[39] The severity of symptoms can be measured by using the Edmonton Symptom Assessment Scale (ESAS), a patient-reported outcome measure for symptoms prevalent in the palliative phase which is manageable at the ED.[40,41] Although the ESAS is not yet validated in the ED setting, a study by Barbera et al. shows that poor symptom burden scores were associated with higher usage of the ED, suggesting that patients visit the ED particularly with high palliative care needs which should be acted upon as soon as possible.[42]

To identify patients in whom palliative care should be initiated, survival prediction tools such as the Surprise Question, and prediction scores such as the Palliative Prognostic Score (PaP), Palliative Prognostic Index (PPI), Glascow Prognostic Score (GPS) and Prognosis in Palliative Care Study (PiPS) are described.[18.43] However, these tools are not validated in patients with advanced cancer visiting the ED. To facilitate appropriate and ED-initiated palliative care, we constructed a flowchart to help ED staff identify advanced cancer patients with urgent palliative care needs (Fig. 1). In this flowchart, factors from the current study associated with approaching death, suggesting urgent palliative care needs, are depicted: primary lung tumour, dyspnoea, neurologic deterioration, jaundice, and hypercalcemia. Other known triggers for palliative care needs that are easily assessable at the ED were added to the flowchart. In other studies in advanced cancer patients, dyspnoea and respiratory distress are reported as risk factors for approaching death, as are neurological deterioration and gastro-intestinal problems.[9,44,45] Hypercalcemia is probably predictive of death because it can be a marker for progressive disease in patients with bone metastases or paraneoplastic syndromes.[46] Cachexia was associated with approaching death in our univariable model, and delirium was included in the group with neurological deterioration. Although a decline in performance status is a strong predictor for death,[47,48] we could not find an association with death, probably because values were missing for many patients. If advanced cancer patients with urgent palliative care needs are identified at the ED, ED staff may choose to consult the hospital palliative care consultation team. Also, tools for unmet palliative needs screening are available, such as the ‘Screen for Palliative and End-of-life care needs in the Emergency Department (SPEED)’ tool[49] or the shorter 5-SPEED tool[50]. The SPEED is the only palliative care needs assessment tool that is validated for use at the ED; however, it is not yet validated in patients with advanced cancer.

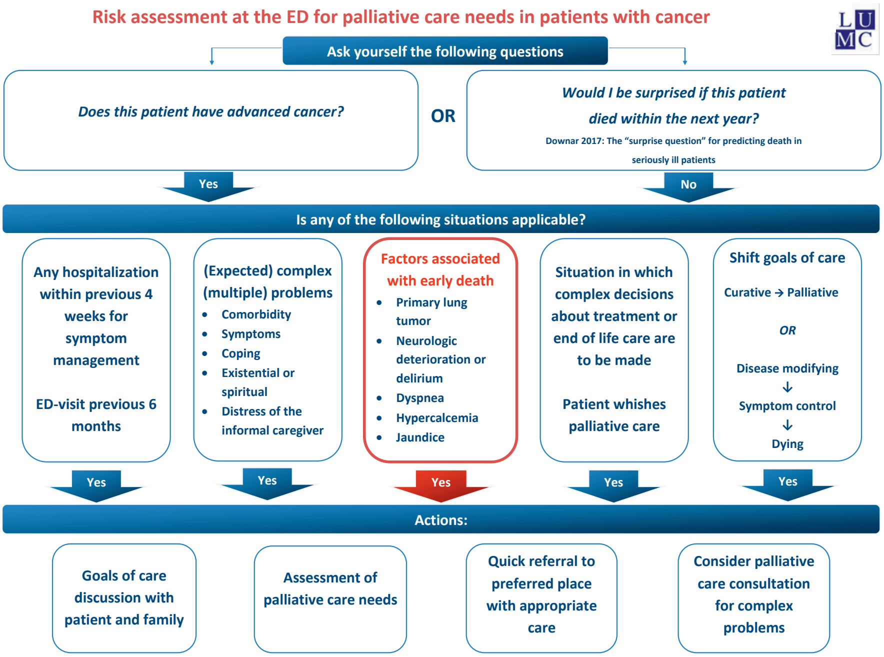

Fig. 1. Risk assessment at the emergency department for palliative care needs in patients with cancer

This pragmatic study gives insight into the end-of-life trajectory of patients with advanced cancer who visit the ED. We are aware that the retrospective design of our study could have led to registration bias and unmeasured confounding. Selection bias was introduced by the choice to limit inclusion to cancer patients in the palliative phase of their disease who died within 3 months after the ED visit. We aimed to describe the population of advanced cancer patients who visited the ED at the end of their life, because especially in those patients, appropriate care should be initiated at the ED. Lastly, because the end-of-life trajectory, especially in the last 3 months, has not been subject to major changes, we consider our data collected from 2011 to 2014 still relevant to the present situation. Further research should be conducted to validate survival prediction tools and needs assessment tools for patients with advanced cancer visiting the ED and to evaluate implementation of models of ED-initiated palliative care.

CONCLUSION

Advanced cancer patients received limited palliative care before visiting the ED in the last 3 months of their life. The ED visit often marked physical deterioration and triggered revision of limitations on life-sustaining treatments. Many patients were hospitalized, and a substantial percentage died within 1 week and in-hospital. Timely recognition of patients at high risk of approaching death and awareness of the potential of ED-initiated palliative care among ED-staff can improve the end-of-life trajectory of these patients.

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Author contributions

Mary-Joanne Verhoef, Nanda Horeweg, Ellen de Nijs and Yvette van der Linden provided the conceptual framework for this study, analysed the data and wrote the manuscript. Marta Fiocco contributed to data-analysis. Corrie Marijnen, Anouk Jochems, Jaap Fogteloo and Christian Heringhaus contributed to data-collection and provided critical comments on the manuscript.

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Conflict of interest

The authors declare that they have no conflict of interest.

Informed consent

As approved by the Medical Ethics Committee of the LUMC and according to Dutch and European law, informed consent from patients was not necessary because of the retrospective design of this study.

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CHAPTER 4

End-of-Life Trajectories of Patients with Haematological Malignancies and Patients with Advanced Solid Tumours visiting the Emergency Department: the Need for a Proactive Integrated Care Approach

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ABSTRACT

Purpose

Patients with haematological malignancies (HM) have more unpredictable disease trajectories compared to patients with advanced solid tumours (ST) and miss opportunities for a palliative care approach. They often undergo intensive disease-directed treatments until the end of life with frequent emergency department (ED)-visits and in-hospital deaths. Insight into end-of-life trajectories and quality of end-of-life care can support arranging appropriate care according to patients' wishes.

Methods

Mortality follow-back study to compare of end-of-life trajectories of HM- and ST-patients who died <3 months after their ED-visit. Five indicators based on Earle et al. for quality of end-of-life care were assessed: intensive anti-cancer treatment <3 months; ED-visits <6 months; in-hospital death; death in the ICU; in-hospice death.

Results

We included 78 HM-patients and 420 ST-patients, median age 63 years, 35% had ECOG performance status 3-4. At the ED, common symptoms were dyspnoea (22%), pain (18%) and fever (11%). After ED-visit, 91% of HM-patients versus 76% of ST-patients were hospitalized (p=0.001). Median survival was 17 days (95%CI 15-19); 15 days in HM-patients (95%CI 10-20) versus 18 days in ST-patients (95%CI 15-21), p=0.028. Compared to ST-patients, HM-patients more often died in-hospital (68% vs 30%, p<0.0001) and in the ICU or ED (30% vs 3%, p<0.0001).

Conclusion

Because end-of-life care is more aggressive in HM-patients compared to ST-patients, a proactive integrated care approach with early start of palliative care alongside curative care is warranted. Timely discussions with patients and family about advance care planning and end-of-life choices can avoid inappropriate care at the end of life.

INTRODUCTION

The disease trajectories of patients with a haematological malignancy (HM) are diverse; from diseases with an acute manifestation and poor survival, to those with a chronic nature. Treatments for HMs, even in patients with a poor clinical condition, are often intensive and are associated with a high risk of severe toxicity (such as graft versus host disease), infection and even death.[1] Because disease trajectories of HM-patients are unpredictable and life-threatening, recognition of those who could benefit from a palliative care approach is complicated.[2-6] As a consequence, HM-patients are seldom referred to palliative care consultation teams (PCCTs) or hospices; and if they are referred, they often die within days or weeks.[2,7,8] It is known that palliative care needs of HM-patients are often unmet.[9] According to the definition of the World Health Organization, the aim of a palliative care approach is to improve quality of life of both patients and family; in addition, it can concur with curative systemic treatment along the disease trajectory.[10] This approach includes conversations about the end of life, supportive care, symptom management and psychosocial support.[9] Insight into the end-of-life trajectory of HM-patients may help identifying cues for initiation of a palliative care approach.

With the occurrence of disease progression or metastases, the palliative phase in patients with a solid tumour (ST) is easier to identify.[6,7,11] According to Murray, their physical decline is stable and predictable until a steep and short period of decline before death. During the stable phase health care providers can proactively assess and support palliative care needs and the end of life.[12] A palliative care approach has been shown effective in a various populations of ST-patients in improving quality of life, symptom burden and even survival.[13-15] In HM-patients, palliative care can improve the quality of life after hematopoietic stem cell transplantation already after two weeks, as a randomized controlled study by El-Jawahri et al. showed.[16] However, literature indicates that HM-patients need a different proactive approach for early palliative care than the disease trajectory of advanced ST-patients. Conceptual models of integrated palliative care for HM-patients depict palliative care as concurrent with curative care to aim for both cure and care.[17-19] So-called trigger-events can help identifying HM-patients with palliative care needs to arrange appropriate care.[20] An ED-visit is shown to be a potential trigger.[21]

Many HM-patients are urged to visit the emergency department (ED) with uncontrollable symptoms or a high symptom burden at home. Consecutively, they are often admitted to the hospital or even to an intensive care unit (ICU), where many of them die.[2,22,23] These situations can diminish the quality of the end of life of HM-patients and their families.[24] To measure the quality of end-of-life care provided to patients with incurable diseases, Earle et al. constructed the following indicators: receiving chemotherapy in the last 14 days of life; starting a new chemotherapy in the last 30 days of life; >1 emergency room visit in the last month of life; >1 hospitalization in the last month of life; ICU-admission in the last month of life; death in an acute care hospital; lack of hospice-admission; admission to hospice <3 days before death.[24,25]

The primary objective of this study was to provide insight into the end-of-life trajectory of HM-patients visiting the ED during the last three months of life and to compare with ST-patients. Secondary objective was to compare the quality of end-of-life care in HM- and ST-patients.

PATIENTS AND METHODS

Setting

This mortality follow-back study was conducted at Leiden University Medical Center (LUMC) in Leiden, the Netherlands. LUMC's ED is open 24 hours a day, 7 days a week. On average, 80 patients visit the ED every day and about 30.000 patients are evaluated every year. Since 2011, LUMC has a palliative care consultation team (PCCT), which is available to all departments of our centre for consultation after patients are referred by their health care professional. This study was part of a larger study on end-of-life trajectories of all patients visiting the ED between 2011 and 2013, approved by LUMC's Committee of Medical Ethics on May 27, 2013. Written consent was not required according to Dutch Law (WGBO, article 458) and European Law (General Data Protection Regulation).

Patients

All adult HM-patients who died within three months after their last ED-visit were included. They were compared to ST-patients with advanced cancer, which was defined as not having any curative options or receiving anti-cancer treatment not aimed at curation. Detailed analysis of ST-patients is published elsewhere.[26] The period of three months was chosen because in the Netherlands, an estimated life-expectancy of <3 months justifies referral to intensive palliative care at home, in nursing homes and in hospices. Data-collection occurred from May 2011 - January 2013.

Data collection

For transparent and solid data collection, a code book was designed by two members of our PCCT which contained inclusion and exclusion criteria and description and coding of all variables.[27] Characteristics of disease, referral, ED-visit, and follow-up from ED-arrival until death were extracted from electronic patient records (EPRs) of eligible patients by four trained research assistants. One expert of the PCCT checked for interrater agreement. EPRs were searched for any correspondence with general practitioners (GPs) or PCCT-consultations during the three months before the ED-visit and proactive symptom-management plans in files or letters up to six weeks before the ED-visit. Limitations on life-sustaining treatments (LSTs) were orders on no resuscitation; no ventilation; and no admission to the intensive care unit (ICU). LST-discussions did not occur routinely and notes about LSTs were collected by the research assistants. Arrival at the hospital within office hours was defined as from Monday to Friday between 8 am and 6 pm. Performance status was scored using the Eastern Cooperative Oncology Group (ECOG)-scale.[28] The main symptom was defined as the referring symptom reported by the attending physician and is part of the structure of reporting in the EPR. This symptom was considered 'new' if it was not mentioned in the EPR three months before the ED-visit; it was considered 'acute' if the onset of the symptom was <24h. The clinical diagnosis was defined as the conclusion reported by the attending physician in the EPR. Date and place of death were obtained from EPRs. Cause of death in HM-patients was discussed between one expert of the PCCT (EN) and a haematologist (CO) until agreement was reached. Cues for proactive care were communication about the patient's condition between a health care professional or PCCT of the hospital and the patient's general practitioner (GP) via a letter, telephone, or transfer; proactive care plans (care plan for anticipation of symptoms; care plans informing the general practitioner, care plans written by the PCCT; PCCT-referrals); and limitations on LSTs before the current ED-visit. Quality of end-of-life care was assessed using indicators for proactive end-of-life care and indicators of Earle et al.: intensive anti-cancer treatment in the previous 3 months before the ED-visit (intensive anti-cancer treatments include chemotherapy, targeted therapy, stem cell transplantation and surgery); the number of ED-visits in the 6 months before the current ED-visit; in-hospital death; death in an acute hospital department (the ED or the ICU); death in a hospice (as a positive measure).[24]

Statistics

Characteristics of patients, referrals, ED-visits, and follow-up were analysed using descriptive statistics. To test differences between HM- and ST-patients, we performed Chi-square tests for nominal variables; Mann-Whitney U tests for not-normally distributed continuous or ordinal variables; and Fisher-Freeman-Halton tests for variables with three or more categories. Kaplan-Meier's methodology was used to estimate survival from the ED-visit and survival between HM-patients and ST-patients was tested using a log-rank test. Complete case analyses were performed, using SPSS 23.0 software and a two-sided p-value <0.05 was considered statistically significant.

RESULTS

Patient and disease characteristics

Seventy-eight HM-patients and 420 ST-patients died within three months after their ED-visit (Table 1); more men were in the HM-group (68% versus 55% of ST-patients, p=0.026), median age was 63 years (range: 22-94 years). ECOG-performance score did not differ between HM- and ST-patients. Acute myeloid leukaemia and multiple myeloma were the most common HM-types (26% and 17%, respectively); most solid tumours were located in the digestive tract (27.6%) and in the lung (16.0%; Appendix 1). Before the ED-visit, limitations on life-sustaining treatments (LSTs) were discussed with 171 patients (34.3%): with 13 (16.7%) HM-patients and 158 (37.6%) ST-patients (p<0.0001). Four (5.1%) HM-patients and 142 ST-patients (33.8%) had documented limitations; 'no limitations' were documented in 9 (11.5%) HM-patients and 16 (3.8%) ST-patients (p<0.0001). Up to three months before the ED-visit, the PCCT was consulted in 27 patients (1 HM-patient and 26 ST-patients, p=0.10). Communication via letters, telephone and transfers between medical specialists and the patient's GP had occurred in 67 (85.9%) HM-patients and 332 (79.0%) ST-patients (p=0.15). Proactive care plans were documented for 13 (16.7%) HM-patients and 66 (15.7%) ST-patients (p=0.83).

Table 1. Characteristics of 78 patients with a haematological malignancy and 420 patients with a solid tumour visiting the emergency department.

	Total n=498		**HM-patients n=78**		**ST-patients n=420**		
Characteristics	**n**	**(%)**	**n**	**(%)**	**n**	**(%)**	**P-value**
Male	282	(56.6)	53	(67.9)	229	(54.5)	0.026
Age in years, median (range)	63	(22-94)	61	(27-94)	61	(22-92)	0.147
Disease-modifying treatment in the past 3 months[a]							
Chemotherapy	202	(40.6)	34	(43.4)	168	(40.0)	0.554
Radiotherapy	118	(23.7)	14	(17.9)	104	(24.8)	0.182
Targeted therapy/immunotherapy	96	(19.3)	21	(26.9)	75	(17.9)	0.065
Stem-cell transplantation	10	(2.0)	9	(11.5)	1	(0.2)	<0.0001
None	125	(25.1)	14	(17.9)	111	(26.4)	0.102
Limitations on LSTs[b]							<0.0001
Discussed, no documented limitations	25	(5.0)	9	(11.5)	16	(3.8)	
Discussed, documented limitations	146	(29.3)	4	(5.1)	142	(33.8)	
Not discussed	327	(65.7)	65	(83.3)	262	(62.4)	

Table 1. Characteristics of 78 patients with a haematological malignancy and 420 patients with a solid tumour visiting the emergency department. (continued)

	Total n=498		**HM-patients n=78**		**ST-patients n=420**		
Characteristics	**n**	**(%)**	**n**	**(%)**	**n**	**(%)**	**P-value**
PCCT consulted during last 3 months	27	(5.4)	1	(1.3)	26	(6.2)	0.100
Proactive symptom-management plan in the prior 6 weeks	62	(12.4)	11	(14.1)	51	(12.1)	0.612
Number of ED-visits during the last 6 months, median (range)	1	(0-9)	1	(0-9)	1	(0-7)	0.147
Patient had a family caregiver							0.608
Yes	433	(86.9)	67	(85.9)	366	(87.1)	
No	31	(6.2)	6	(7.7)	25	(6.0)	
Unknown	34	(6.8)	5	(6.4)	29	(6.9)	
Patient had homecare before the ED visit							0.462
Yes	110	(22.1)	19	(24.4)	91	(21.7)	
No	280	(56.2)	44	(56.4)	236	(56.2)	
Unknown	108	(21.7)	15	(19.2)	93	(22.1)	
Living situation							0.120
Alone	90	(18.1)	10	(12.8)	80	(19.0)	
With someone	369	(74.1)	65	(83.3)	304	(72.4)	
Unknown	39	(7.8)	3	(3.8)	36	(8.6)	
Housing							0.075
Home	447	(89.8)	66	(84.6)	381	(90.7)	
Residential home	9	(1.8)	2	(2.6)	7	(1.7)	
Nursing home	18	(3.6)	6	(7.7)	12	(2.9)	
Hospice	6	(1.2)	1	(1.3)	5	(1.2)	
Other	5	(1.0)	2	(2.6)	3	(0.7)	
Unknown	13	(2.6)	1	(1.2)	12	(2.9)	
ECOG-performance score							0.078
0-2	90	(18.1)	17	(21.8)	73	(17.4)	
3-4	173	(34.7)	50	(64.1)	123	(29.3)	
Unknown	235	(47.2)	11	(14.1)	224	(53.3)	

List of abbreviations: ED: emergency department; HM: haematological malignancy; ST: solid tumour; IQ-range: interquartile range; LSTs: life-sustaining treatments; PCCT: palliative care consultation team; ECOG: Eastern Cooperative Oncology Group.

[a] Numbers may exceed 100% because patients may have received multiple disease-modifying therapies in the past.

[b] Limitations on LSTs were defined as orders on: no resuscitation; no ventilation; and no admission to the intensive care unit.

Referral characteristics

Patients or their family initiated the ED-visit in 37.3% (Table 2). Two hundred-and-fifty-eight (51.8%) came outside office hours. Most common main symptoms were dyspnoea (22.1%), pain (17.5%) and fever (11.2%). HM-patients more often presented with fever (23.1% versus 9.0% of the ST-patients, p=0.001); ST-patients more often with nausea or vomiting (9.3% versus 2.6% of the HM-patients). Patients had a median of 2 symptoms.

Table 2. Emergency department-referral characteristics of 78 patients with a haematological malignancy and 420 patients with a solid tumour.

	Total n=498		**HM-patients n=78**		**ST-patients n=420**		
ED-referral	**n**	**(%)**	**n**	**(%)**	**n**	**(%)**	**P-value**
Referrer							0.420
GP or elderly care physician	189	(38.0)	25	(32.1)	164	(39.0)	
Medical specialist	123	(24.7)	23	(29.5)	100	(23.8)	
Patient or informal caregiver	186	(37.3)	30	(38.5)	156	(37.1)	
Referral outside office hours	258	(51.8)	40	(51.3)	218	(51.9)	0.919
Main symptom							
Dyspnoea	110	(22.1)	22	(28.2)	88	(21.0)	0.166
Pain	87	(17.5)	9	(11.5)	78	(18.6)	0.117
Fever	56	(11.2)	18	(23.1)	38	(9.0)	0.001
Neurologic deterioration[a]	41	(8.4)	8	(10.3)	33	(7.9)	0.491
Nausea or vomiting	41	(8.2)	2	(2.6)	39	(9.3)	0.025
Weakness or loss of strength	25	(5.0)	6	(7.7)	19	(4.5)	0.256
Bleeding	23	(4.6)	3	(3.8)	20	(4.8)	>0.999
Obstipation or diarrhoea	17	(3.4)	1	(1.3)	16	(3.8)	0.493
Fatigue	12	(2.4)	4	(5.1)	8	(1.9)	0.102
Difficulty swallowing or passage problems	9	(1.8)	0	(0.0)	9	(2.1)	0.367
Seizure	9	(1.8)	1	(1.3)	8	(1.9)	>0.999
Oedema	8	(1.6)	0	(0.0)	8	(1.9)	0.617
Ascites	7	(1.4)	0	(0.0)	7	(1.7)	0.603
Other	53	(10.6)	4	(5.1)	49	(11.7)	0.062
Admission for							
New problem[b]	254	(51.0)	35	(44.9)	219	(52.1)	0.238
Acute problem[c]	179	(35.9)	24	(30.8)	155	(36.9)	0.295
Number of symptoms, median (range)	2	(0-8)	2	(0-8)	2	(0-7)	0.055

List of abbreviations: HM: haematological malignancy; ST: solid tumour; ED: emergency department; GP: general practitioner.

[a] Confusion, drowsiness, reduced consciousness.

[b] Not reported in the patient records in the last three months.

[c] Onset within the last 24 hours.

Visit and follow-up characteristics

Patients underwent diagnostic imaging in 64.1% and laboratory tests in 84.1% (Table 3). Most patients were diagnosed with infection or fever (24.5%), bronchopulmonary insufficiency (14.3%) or renal insufficiency (11.8%). In HM-patients, treatment for their main symptoms was initiated at the ED more often than in ST-patients (69.2% versus 54.8%, p=0.010). After their ED-visit, more HM-patients were hospitalized than in ST-patients (91.0% versus 76.0%, p=0.001). The ED-visit triggered discussions about LSTs in both HM-patients and ST-patients. After the ED-visit, LSTs were documented for 41 (52.6%) HM-patients and 307 (73.1%) ST-patients (p<0.0001). Among these patients, 39 (95.1%) HM-patients and 297 (96.7%) ST-patients had limitations on LSTs (p=0.64). Median survival from the ED-visit was 17 days (95% CI 15-19) and was significantly shorter in HM-patients (15 days versus 18 days, p=0.028). In-hospital death occurred in 67.9% of the HM-patients versus 29.5% of the ST-patients; HM-patients died at home in 15.4% versus 38.3% of the ST-patients (p<0.0001). In HM-patients, causes of death were disease progression (46.2%), treatment toxicity (39.7%), or both (9.0%).

Quality of end-of-life care

Quality of end-of-life care in HM- and ST-patients is shown in Table 4. Intensive anti-cancer treatment was administered to 375 (72.4%) of all patients up to 6 months before the ED-visit; to 75.6% of the HM-patients versus 71.8% of the ST-patients, p=0.48. HM-patients died more often in-hospital compared to ST-patients (67.9% versus 29.5%, p<0.0001), in an acute hospital setting (29.5% versus 2.7%, p<0.0001) and less often in a hospice (2.6% versus 10.5%, p=0.011).

Table 3. Emergency department-visit and follow-up characteristics of 78 patients with a haematological malignancy and 420 patients with a solid tumour.

	Total n=498		HM-patients n=78		ST-patients n=420		
ED-visit	**n**	**(%)**	**n**	**(%)**	**n**	**(%)**	**P-value**
Diagnostic imaging	319	(64.1)	53	(67.9)	266	(63.3)	0.326
Laboratory tests	419	(84.1)	69	(88.5)	350	(83.3)	0.204
Clinical diagnosis							
Infection or fever	122	(24.5)	36	(46.2)	86	(20.5)	<0.0001
Bronchopulmonary insufficiency	71	(14.3)	17	(21.8)	54	(12.9)	0.051
Renal insufficiency or hydronephrosis	59	(11.8)	12	(15.4)	47	(11.2)	0.308
Cachexia	44	(8.8)	4	(5.1)	40	(9.5)	0.177
Pleural effusion	36	(7.2)	5	(6.4)	31	(7.4)	0.750
Ascites	35	(7.0)	1	(1.3)	34	(8.1)	0.010
Bleeding	33	(6.6)	3	(3.8)	30	(7.1)	0.250
Jaundice	24	(4.8)	1	(1.3)	23	(5.5)	0.151
Neuropathy or plexopathy	20	(4.0)	3	(3.8)	17	(4.0)	>0.999
Ileus or passage disturbances	18	(3.6)	0	(0.0)	18	(4.3)	0.091
Urine retention	14	(2.8)	1	(1.3)	13	(3.1)	0.707
Seizure	14	(2.8)	1	(1.3)	13	(3.1)	0.707
Fracture	10	(2.0)	0	(0.0)	10	(2.4)	0.375
Deep venous thrombosis	8	(1.6)	1	(1.3)	7	(1.7)	>0.999
Coma	8	(1.6)	0	(0.0)	8	(1.9)	0.617
Delirium	8	(1.6)	2	(2.6)	6	(1.4)	0.365
Pulmonary embolism	8	(1.6)	1	(1.3)	8	(1.9)	0.617
Spinal cord compression	5	(1.0)	0	(0.0)	5	(1.2)	>0.999
Treatment for main symptom initiated at ED	284	(57.0)	54	(69.2)	230	(54.8)	0.010
Time spent at ED in hours:minutes, median (range)	3:32	(0:12-18:01)	3:37	(0:42-12:12)	3:39	(0:12-18:01)	0.708
Follow-up							
ED-visit followed by hospital admission	390	(78.3)	71	(91.0)	319	(76.0)	0.001
Observed survival in days, median (95% C.I.)	17	(15-19)	15	(10-20)	18	(15-21)	0.028
Place of death							<0.0001
Clinical ward	143	(28.7)	30	(38.5)	113	(26.9)	
ICU or ED	34	(6.8)	23	(29.5)	11	(2.6)	
Home	173	(34.7)	12	(15.4)	161	(38.3)	
Nursing or residential home	12	(2.4)	3	(3.8)	9	(2.1)	
Hospice	47	(9.4)	2	(2.6)	45	(10.7)	
Unknown	89	(17.9)	8	(10.3)	81	(19.3)	

List of abbreviations: ED: emergency department; HM: haematological malignancy; ST: solid tumour; ICU: intensive care unit.

Table 4. Comparison of indicators of quality of end-of-life care between 78 patients with a haematological malignancy and 420 patients with a solid tumour.

Indicators of quality of end-of-life care	**Total n=498**		**HM-patients n=78**		**ST-patients n=420**		
	n	**(%)**	**n**	**(%)**	**n**	**(%)**	**P-value**
Intensive anti-cancer treatment[a]	375	(72.4)	59	(75.6)	316	(71.8)	0.48
Number of ED-visits[b], median (range)	1.00	(0-9)	1.00	(0-9)	1.00	(0-7)	0.12
In-hospital death	183	(35.3)	53	(67.9)	130	(29.5)	<0.0001
Death in an acute hospital setting[c]	35	(6.8)	23	(29.5)	12	(2.7)	<0.0001
Death in hospice	48	(9.2)	2	(2.6)	46	(10.5)	0.011

List of abbreviations: HM: haematological malignancy; ST: solid tumour; ED: emergency department; ICU: intensive care unit

[a] Number of intensive anti-cancer treatments received in the 3 months before ED-visit. Intensive anti-cancer treatments included: chemotherapy, targeted therapy, stem cell transplantation, surgery, radiotherapy, hormonal therapy, nuclear therapy.

[b] Number of ED-visits in 6 months before current ED-visit.

[c] Acute hospital settings included the ED and the ICU.

DISCUSSION

This study gives insight into the disease trajectory of haematological malignancy (HM)-patients and in the differences compared to the disease trajectory of patients with a solid tumour (ST) visiting the ED in the last three months of their lives. Limitations on life-sustaining treatments (LST) were often not discussed in HM-patients before their ED-visit; and if these were discussed, patients often had no limitations on LSTs. End-of-life care was considerably more aggressive in HM-patients compared to ST-patients. HM-patients had a worse survival than ST patients, and more often died in-hospital and in the ICU and seldom in a hospice.

Our results show that end-of-life care implicates aggressive in HM-patients: they scored poorly on five of the indicators of quality of end-of-life care by Earle.[24] Our findings are in accordance with international literature reporting that HM-patients receive intensive treatments until death. In a study by Hui et al., HM-patients received significantly more chemotherapy (21%) and targeted therapy (17%) than ST-patients (6% and 5%, respectively).[2] Other studies report that HM-patients often received G-CSF, blood transfusions and antibiotics and underwent diagnostic imaging, blood sampling, endoscopy and bone marrow examination in the last seven days of life.[23,29] A French study in patients who died from metastatic lung cancer showed that end-of-life care was less aggressive the earlier palliative care needs were reported in their EPRs: patients sooner stopped anticancer treatment and they underwent less often invasive ventilation.[30] In patients with pancreatic cancer in the last thirty days of life who were referred to a palliative care service, those with an early referral to a palliative care team visited the ED less often and were less often hospitalized.[31] It thus seems that when palliative care is integrated into oncology care, ST-patients are at a lower risk of aggressive end-of-life care. In our study, limitations on LSTs were seldom discussed with HM-patients and remarkably, if it was discussed, it was often explicitly stated in their electronic patient dossiers that there were no limitations on LSTs. A recent integrative systematic review provided more insight into the aspects of this 'curative mindset': haematologists feel uncomfortable with hospice-referrals and discussing approaching death with patients and family; disease-progression is considered as personal failure; and they are concerned that mentioning palliative care early in the disease trajectory might scare patients and their relatives.[6] A qualitative study by Prod'homme et al. showed that end-of-life discussions are avoided by haematologists as long as cure is possible; these discussions are perceived to damage the doctor-patient relationship, especially when the patient's prognosis is uncertain.[32] In addition, haematologists interpret palliative care more often as end-of-life care than medical oncologists do and are less used to involve a palliative care specialist than medical oncologists.[33] It is known that if HM-patients are referred to palliative care, it generally occurs very late in their disease trajectory.[3,7,11] Although a curative care approach towards HM-patients could be appropriate, the way it is currently practiced discourages timely initiation of a palliative care approach and conversations about the end of life. El-Jawahri et al. reported that 27% of the hospital-admissions in AML-patients could have been avoided.[34] Reasons were: being discharged too soon after the previous admission, visits for problems that would have been manageable at home and the lack of timely out-patient follow-up appointments. These reasons are starting points for initiating a palliative care approach to avoid possible aggressive and harmful treatments in vulnerable patients.

Our study suggests that in many patients the ED-visit marked deterioration and a transition in disease trajectory and often even the start of the dying phase. After the ED-visit or following hospital-admission, limitations on LSTs were discussed and documented in 73% of the ST-patients and 53% of the HM-patients. Although efforts were made to discuss these LSTs, still 36% of the HM-patients were subsequently transferred to the ICU. This is in line with literature demonstrating that HM-patients are frequently and more often admitted to ICUs than ST-patients (39% and 8%, respectively).[2] Failure to recognize patients in the end-of-life phase makes them at risk of receiving aggressive treatments in the hospital and may even result in death: in our study, 33% of the HM-patients died in the ICU, compared to 4% of the ST-patients ($p<0.0001$).[2] Sixty-nine percent of our HM-patients died in the hospital and 40% died as a result of treatment toxicity. Howell et al. showed that, compared to ST-patients, HM-patients had a twice higher risk to die in the hospital.[22] Our findings confirm that HM-patients have unpredictable disease trajectories that can suddenly change from curative to dying: most of our patients died shortly after the ED-visit with a median survival of only 15 days. Reasons for difficulties to predict survival and to recognize the transition to the end-of-life trajectory are: possibly reversible conditions such as infections, increasing availability of systemic therapies that stimulate continuance of active treatment and increase the risk of lethal complications.[1,35] Long-lasting physician-patient relationships are also known to hamper accurate recognition of deterioration.[6] The combination of these factors makes it difficult for physicians to recognize approaching death in HM-patients and to timely prepare them for their approaching death.

A proactive integrated care approach

We advocate, as Zimmermann, Bruera, LeBlanc, El-Jawahri, Chung and Button do, the use of an integrated care approach with two concurrent tracks: a curative approach and palliative care approach (Figure 1).[16-19,36,37] Integrated care should be initiated early in the disease trajectory if the disease is potentially life-threatening (which can be at diagnosis). The first track consists of conventional disease treatment aimed at cure. The second track consists of supportive care following the four-dimensional principles of palliative care: physical, psychological, social, and spiritual. Importantly, the second track also includes discussions about future problems, treatment choices, hospital-admissions, LSTs and place of death. The palliative care approach has shown to benefit symptom-control[37] and quality of life,[38] to decrease ED-visits, hospital- and ICU-admissions and in-hospital deaths[39,40] and might even prolong survival.[41] In the integrated care approach, multidisciplinary discussions and communication across specializations within and outside the medical field are crucial to satisfy care needs. The randomized clinical trial by El-Jawahri et al. demonstrated that in-patient palliative care improved the quality of life of HM-patients already within two weeks after hematopoietic stem cell transplantation had taken place.[16]

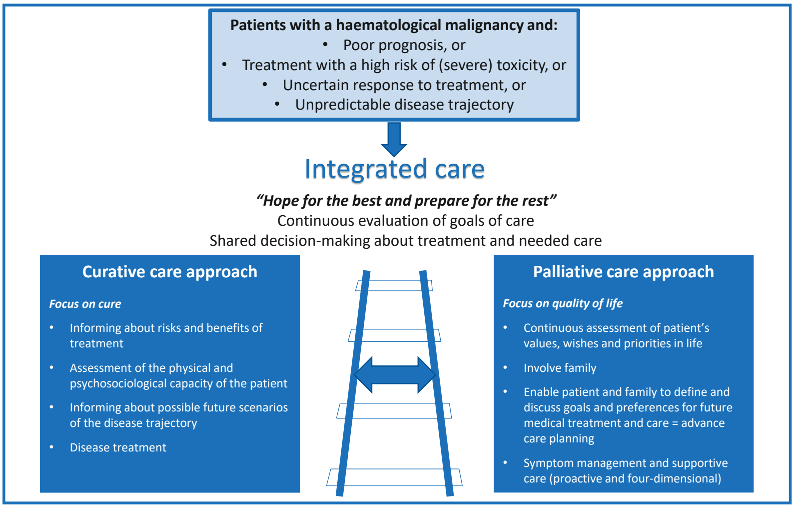

Figure 1. A proactive integrated care approach for patients with a haematological malignancy: a curative and a supportive track.

Our pragmatic study provides insight into the care for HM-patients visiting the ED in their end-of-life trajectory and compared is with the disease trajectory of ST-patients. The inclusion of only those patients who died within 3 months after the ED-visit is inherent to the mortality-follow-back design of this study, but it has introduced selection bias. Although data were collected from 2011-2013, they are still relevant since new life-prolonging systemic treatments only further emphasize the need for an integrated care approach. Further research should be directed to identifying the specific palliative care needs of HM-patients and their families and developing interventions to address to those.

CONCLUSION

HM-patients who visited the ED in the last 3 months of life are more often hospitalized and die in-hospital compared to ST-patients. To improve care during the end-of-life trajectory, especially for HM-patients, palliative care should be timely integrated in standard oncological care.

Authors' Note

As approved by the Medical Ethics Committee of the LUMC and according to Dutch and European law, informed consent from patients was not necessary because of the retrospective design of this study.

Declaration of Conflicting Interests

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CHAPTER 5

Surprise Question and performance status indicate urgency of palliative care needs in patients with advanced cancer at the Emergency Department: an observational cohort study

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ABSTRACT

Background
The surprise question (SQ), ‘Would I be surprised if this patient died within 1 year?’, is a simple instrument to identify patients with palliative care needs. The SQ-performance has not been evaluated in patients with advanced cancer visiting the emergency department (ED).

Objective
To evaluate SQ’s test characteristics and predictive value in patients with advanced cancer visiting the ED.

Design
Observational cohort study.

Setting
Patients >18y with advanced cancer in the palliative phase visiting the ED of an academic medical centre.

Methods
Attending physicians answered the SQ (not surprised (NS) or surprised (S)) and estimated ECOG-performance status. Disease, visit, and follow-up characteristics were retrospectively collected from charts. SQ’s sensitivity, specificity, positive (PPV) and negative predictive values (NPV) and Harrell’s c-index were calculated. Prognostic values of SQ and other variables were assessed using Cox proportional hazards models.

Results
Two-hundred-and-forty-five patients were included (203 NS (83%) and 42 S (17%)), median age 62 years, 48% male. Follow-up on overall survival was updated until February 2019. At ED-entry, NS-patients had worse ECOG-performance and more symptoms. At study closure, 233 patients had died (95%). Median survival was 3.0 months for NS-patients (IQ-range 1-8); 9.0 months for S-patients (IQ-range 3-28) ($p<0.0001$). SQ-performance for 1-year mortality: sensitivity 89%, specificity 40%, PPV 85%, NPV 50%, c-index 0.56, HR 2.1 for approaching death. ECOG 3-4 predicted death in NS-patients; addition to the SQ improved c-index (0.65); sensitivity (40%), specificity (92%), PPV (95%), NPV (29%)).

Conclusions
At the ED, the SQ plus ECOG 3-4 helps identifying patients with advanced cancer and a limited life-expectancy. Its use supports initiating appropriate care related to urgency of palliative care needs.

INTRODUCTION

Palliative care can improve the quality of life and satisfy care needs of patients with advanced disease and family.[1-3] Initiating palliative care early in the disease trajectory of advanced cancer is accepted to timely prepare them for deterioration and death.[4,5] However, identification of patients with limited life-expectancy and palliative care needs is difficult. Previous studies indicate that initiation of palliative care in patients with advanced cancer can follow 'trigger-moments', such as visits to the emergency department (ED).[6,7] Patients with advanced cancer visit the ED more often in the last year of life.[8,9] Since ED-triggered palliative care effectively improves their quality of life, identifying these patients at the ED can be useful.[10] Familiar screening tools identifying patients with advanced cancer having palliative care needs are the Supportive and Palliative Care Indicators Tool (SPICT), Necesidades Paliativas (NECPAL) identification tool, Golden Standards Framework – Proactive Identification Guidance (GSF-PIG), Radboud indicators for Palliative Care Needs (RADPAC) and a Centre to Advance Palliative Care's checklist.[11-15] However, these screening tools may be too elaborate for use at the ED. Moreover, prediction scores for approaching death focus on prediction of death within a few days or weeks, missing out the opportunity to initiate palliative care early.[16-18]

An example of a simple tool to timely identify patients with palliative care needs is the 'Surprise Question' (SQ): 'Would I be surprised if this patient died within one year?'. The SQ was developed for identification of palliative care needs by estimating the probability that the patient would die from current or future physical problems in the next year.[19,20] A 'not surprised' (NS)-answer should trigger further screening for palliative care needs.[21,22] In a qualitative study, attending ED-physicians indicated that the SQ was easy to use and could influence discussions about care delivery and goals of care.[23] In addition, answering the SQ is more related to 'gut feeling', than on stern estimation of remaining life-expectancy of a patient.[24] Although the aim of the SQ is to mark patients with palliative care needs, focus in research lies on the performance of the SQ to screen for patients dying within one year.[21,25] Studies have shown that the SQ is accurate in screening dialysis and heart failure patients.[20,26] Cancer patients with NS-answers in oncology outpatient wards[27] and general practices[28] had hazard ratios (HR) of death <1yr of 7.8 and 7.0, respectively. The SQ also identifies hospitalized patients with hematologic and solid tumours with unmet palliative care needs.[29]

A recent meta-analysis of Downar et al.[20] demonstrated that, in the overall population of patients with advanced cancer, the SQ might not be sufficient as a screening tool for death within one year. It lacked sensitivity and therefore under-estimated the number of patients with palliative care needs (sensitivity 67.0%, specificity 80.2%, positive predictive value 37.1%, negative predictive value 93.1%).[21] The SQ may be more accurate combined with other indicators of palliative care needs, such as symptoms prevalent in the palliative phase, performance status and indicators of increased utilization of formal and informal care.[11,13,30-34] NECPAL and GSF-PIG combine the SQ with these indicators for screening of patients with palliative care needs; however, it is not yet published whether the combination of these indicators with the SQ improves the performance of these screening instruments.[13,30] At the ED, the SQ has been tested in patients with heart failure and in elderly.[35,36] In elderly, SQ's c-statistic increased after adding the physician's working experience and the PREDICT-criteria for identification of elderly with a limited life-expectancy.[36] To our knowledge, the performance of the SQ with and without other indicators of palliative care needs has not been studied yet in adult patients with advanced cancer visiting the ED.

Objectives of this study were to evaluate the prognostic value of the SQ in patients with advanced cancer visiting the ED; and to study the yield of adding other predictors for approaching death.

PATIENTS AND METHODS

Setting and patients

This cohort study took place at the ED of a Dutch academic medical centre, where acute care is offered 24/7. On average, eighty patients are seen per day for both oncological and non-oncological problems. All ED-visits from May 2013 to July 2014 were prospectively screened. Inclusion criteria for patients were: diagnosis of cancer in the palliative phase[2], i.e. metastasized or incurable cancer; who were at least 18 years of age. Patients with a haematological malignancy or who were not admitted to the ED for the Medical Oncology Department were excluded. Only the first ED-visits of patients were included; subsequent ED-visits by the same patients were excluded. Follow-up on overall survival was updated until February 2019. Survival data were obtained from the EPRs, which is monthly updated via the Dutch population register.

Data collection

After the ED-visit, a list of patients who visited the ED were screened if they met the inclusion criteria by two trained research assistants; if they did, attending physicians were sent an e-questionnaire with the SQ. E-questionnaires were sent within 1 working day to limit recall bias. Patients were divided into two groups according to the SQ: 'Would I be surprised if this patient died within one year?'; 'NS-patients' of whom the physician would not be surprised, and 'S-patients' of whom the physician would be surprised. For NS-patients, the e-questionnaire proceeded with the Eastern Cooperative Oncology Group

(ECOG) scale.[37] Data abstraction was performed using a code book about which consensus was reached among members of the scientific team of the hospital's PCCT. The code book contained definitions of all variables for data collection and data were imported into a digital database accordingly. Four chart abstractors were trained on how to use the code book. One expert of the PCCT monitored the work of the chart abstractors, was available in cases of doubt and performed random checks to assess interrater agreement. Electronic patient records (EPRs) were assessed to collect additional patient-, referral-, ED-visit- and follow-up characteristics and ECOG performance score of S-patients. The disease phase was evaluated and classified according to Lynn and Adamson: disease-modifying phase (anti-cancer treatment to prolong life and/or symptom management); symptom-management phase (treatment directed to symptom-relief); or terminal phase.[38] The EPRs were searched for reports about PCCT-consultations 3 months before the current ED-visit. 'Limitations on life-sustaining treatments (LSTs)' included the codes: 'do-not-resuscitate'; 'do-not-ventilate'; and 'no admission to the intensive care unit' (ICU). Time of arrival at the ED was within office hours if the visit occurred Monday-Friday between 8am-6pm. The 'main symptom' was the referring symptom for the ED-visit according to the attending physician's notes in the EPR. A 'new symptom' was a main symptom not described in the EPR <3 months before the ED-visit. Main symptoms were considered 'acute symptoms' if the onset was within one working day before the ED-visit. Using the Dutch Edmonton Symptom Assessment Scale (ESAS), symptoms were scored as present or absent based on documentation in the EPRs.[39] The clinical diagnosis was defined as the conclusion of the attending physician at the ED.

Statistical analysis

Characteristics of NS- and S-patients were compared using the Chi-square test and Fisher's exact test (nominal variables) and Mann-Whitney U test (ordinal variables and not-normally distributed continuous variables). Survival was estimated using Kaplan-Meier's methodology. A log-rank test was used to compare overall survival between NS- and S-groups.

Prognostic value of the SQ

Two-by-two tables were used to calculate test characteristics (sensitivity, specificity, positive predictive value (PPV) and negative predictive value (NPV)) of the SQ as screening tool for death <1 year. Harrell's c-index was calculated to estimate the discriminative power of the SQ for death <1 year.[40,41]

Addition of other predictors of approaching death to the SQ

To identify predictors of palliative care needs, univariable regression analyses using Cox proportional hazards models were performed to estimate the association between death (from ED-visit) and the following predefined candidate predictors: SQ, poor performance status (ECOG 3-4), acute symptoms, palliative disease phase, symptom-management treatment, home care, ED-visits in the previous six months, limitations on life-sustaining treatments. Next, the SQ and predictors with a p-value of <0.10 in univariable analyses were entered in a multivariable analysis. Discriminative ability of the final multivariable model (including the SQ and any independent predictors) was estimated using Harrell's c-statistic. Akaike's information criterion was calculated to compare the ability of the predictive models with and without SQ to explain the variance in our dataset.[42]

Ethical approval and informed consent

The Committee of Medical Ethics of the LUMC approved this study on May 27, 2013. According to Dutch Law (WGBO, article 458) and European Law (General Data Protection Regulation), written consent from included patients was not required. Data from this study were analysed after de-identification.

RESULTS

Patient and ED-visit characteristics

ED-visits of 245 patients with advanced cancer were included. The attending physician at the ED answered the SQ with 'No' (NS) in 203 patients (83%), and 'Yes' (S) in 42 patients (17%) (Table 1). Overall median age was 62 years (interquartile (IQ-)range: 45-79 years) and 48.2% was male. Compared to S-patients, NS-patients more often received symptom-management therapy (29.6% versus 16.7%, p=0.049), reported more main symptoms at the ED and had a worse clinical condition (ECOG 3-4 in 40% vs. 21%, p=0.034). Most frequently reported ESAS-symptoms were pain (overall 60.8%; NS 64.0% versus S 45.2%, p=0.023), nausea (29.8%; 31.0% versus 23.8%, p=0.46) and shortness of breath (29.8%; 31.0% versus 23.8%, p=0.46). During or after the ED-visit, changes emerged in limitations on LSTs: before the ED-visit, 64 patients (26.1%) had documented limitations on LSTs; after the ED-visit, this had risen to 104 patients (42.4%) (Table 2). Within 1 year, 193 patients (78.8 %) had died: 172 NS-patients (85%), and 21 S-patients (50%). At the end of follow-up, 233 patients had died (95%). Overall median survival was 3.0 months (IQ-range 1-11); 3.0 months for NS-patients (IQ-range 1-8) and 9 months for S-patients (IQ-range 3-28; log-rank p<0.0001, Figure 1).

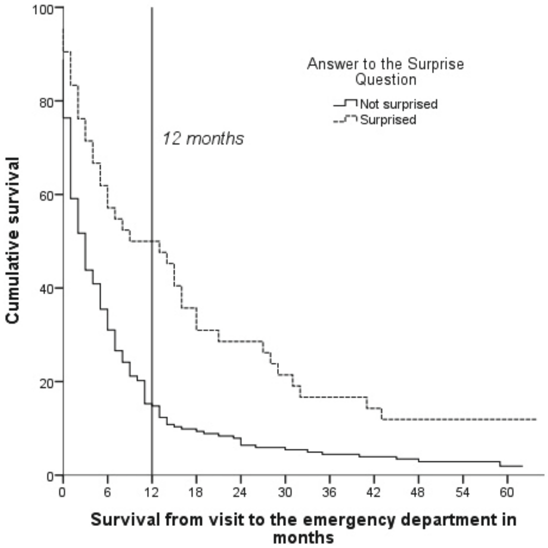

Figure 1. Observed survival of patients with advanced cancer from their first visit to the emergency department.

Table 1. Patient and disease characteristics of patients with advanced cancer visiting the emergency department

	Total (n=245)	NS-patients (n=203)	S-patients (n=42)	P-value
Age, median (IQ-range)	62 (45-79)	62 (53-69)	59 (49.50-69.25)	0.23
Sex, male, n (%)	118 (48.2)	91 (44.8)	27 (64.3)	0.021
Location primary tumour, n (%)				0.001
Breast	29 (11.8)	24 (11.8)	5 (11.9)	
Gynaecologic	27 (11.0)	27 (13.3)	0 (0.0)	
Bowel (gastro-intestinal-colorectal)	75 (30.6)	66 (32.5)	9 (21.4)	
Head/neck	10 (4.1)	7 (3.4)	3 (7.1)	
Lung	14 (5.7)	14 (6.9)	0 (0.0)	
Urologic	31 (12.7)	21 (10.3)	10 (23.8)	
Hematologic	11 (4.5)	6 (3.0)	5 (11.9)	
Unknown	3 (1.2)	3 (1.5)	0 (0.0)	
Other[a]	45 (18.4)	35 (17.2)	10 (23.8)	
Disease phase, n (%)				0.049
Disease-modifying	174 (71.0)	139 (68.5)	35 (83.3)	
Symptom-management	67 (27.3)	60 (29.6)	7 (16.7)	
Terminal	2 (0.8)	2 (1.0)	0 (0.0)	
Unknown	2 (0.8)	2 (1.0)	0 (0.0)	

Table 1. Patient and disease characteristics of patients with advanced cancer visiting the emergency department (continued)

	Total (n=245)	NS-patients (n=203)	S-patients (n=42)	P-value
Anti-cancer treatment in preceding 3 months[b], n (%)				
Local treatment[c], n (%)	69 (28.2)	59 (29.1)	10 (23.8)	0.49
Systemic treatment[d], n (%)	174 (71.0)	146 (71.9)	28 (66.7)	0.50
None	41 (16.7)	33 (16.3)	8 (19.0)	0.66
Informal caregiver available, n (%)	205 (83.7)	168 (82.8)	37 (88.1)	0.59
Homecare, n (%)	36 (14.7)	36 (17.7)	0 (0.0)	0.039
PCCT consulted in preceding 3 months, n (%)	12 (4.9)	11 (5.4)	1 (2.4)	0.70
Number of ED-visits in the preceding 6 months, n (%)				0.88
0 ED-visits	155 (68.3)	128 (63.1)	27 (64.3)	
≥1 ED-visit	90 (36.7)	75 (36.9)	15 (35.7)	
Limitations on LSTs discussed and documented, n (%)	64 (26.1)	62 (30.5)	2 (4.8)	<0.0001
Main symptom, n (%)				
Pain	53 (21.6)	43 (21.2)	10 (23.8)	0.71
Nausea or vomiting	27 (11.0)	25 (12.3)	2 (4.8)	0.19
Constipation	4 (1.6)	4 (2.0)	0	>0.999
Neurologic deterioration or delirium	1 (0.4)	1 (0.5)	0	>0.999
Weakness, loss of strength	7 (2.9)	5 (2.5)	2 (4.8)	0.34
Dyspnoea	34 (13.9)	31 (15.3)	3 (7.1)	0.14
Bleeding or blood loss	19 (7.8)	16 (7.9)	3 (7.1)	>0.999
Fever	48 (19.6)	38 (18.7)	10 (23.8)	0.46
Fatigue	1 (0.4)	1 (0.5)	0	>0.999
Diarrhoea	6 (2.4)	6 (3.0)	0	0.59
Oedema	6 (2.4)	5 (2.5)	1 (2.4)	>0.999
Feeling unwell	18 (7.3)	13 (6.4)	5 (11.9)	0.21
Other	14 (5.7)	10 (4.9)	4 (9.5)	0.27
Referral for new[e] symptom, n (%)	99 (40.4)	68 (33.5)	31 (73.8)	0.001
Referral for acute[f] symptom, n (%)	88 (35.9)	66 (32.5)	22 (52.4)	0.29
Number of symptoms, median (range)	2 (0-7)	2 (1-4)	2 (1-3)	0.030
ECOG performance status, n (%)				0.034
ECOG 0-2	151 (61.6)	119 (58.6)	32 (76.2)	
ECOG 3-4	90 (36.7)	81 (39.9)	9 (21.4)	
Unknown	4 (1.6)	3 (1.5)	1 (2.4)	
ED-visit outside office hours, n (%)	107 (43.7)	93 (45.8)	14 (33.3)	0.13

[a] other tumours (n=45): skin (19, 42.2%); sarcoma (12, 26.7); (retro-)peritoneum (5, 11.1%); eye (3, 6.7%); thymus (2, 4.4%); unknown primary (2, 4.4%); brain (1, 2.2%); ear, nose, throat (1, 2.2%). [b] total number can exceed 100%, as patients can have undergone more than 1 treatment. [c] local treatment: surgery, nuclear therapy, radiotherapy. [d] systemic treatment: chemotherapy, hormonal therapy, stem cell transplantation, targeted-/immunotherapy. [e] "new": not mentioned in electronic patient record in previous 6 months. [f] "acute": onset <24 hours. List of abbreviations: NS: not surprised; S: surprised; PCCT: palliative care consultation team; ED: emergency department; LSTs: life-sustaining treatments

Table 2. Visit and follow-up characteristics of 245 patients with advanced cancer visiting the emergency department

	Total **n=245**	**SQ = no** **n=203**	**SQ = yes** **n=42**	**P-value**
Diagnostic imaging, n (%)	148 (60.4)	119 (58.6)	29 (69.0)	0.65
Laboratory testing, n (%)	201 (82.0)	168 (82.8)	33 (78.6)	0.027
Limitations on LSTs discussed and documented, n (%)	104 (42.4)	102 (50.2)	2 (4.8)	<0.0001
Time spent at the ED in hours (IQ-range)	3:31 (2:37-4:29)	3:30 (2:37-4:29)	3:34 (2:32-4:49)	0.51
Hospitalization after ED-visit, n (%)	186 (75.9)	157 (77.3)	29 (69.0)	0.37
Observed survival after ED-visit in months, median (IQ-range)	3 (1-11)	3 (1-8)	9 (3-28)	<0.0001
Place of death, n (%)				0.50
Home	89 (36.3)	77 (37.9)	12 (28.6)	
Hospice	26 (10.6)	25 (12.3)	1 (2.4)	
Hospital ward	44 (18.0)	37 (18.2)	7 (16.7)	
Intensive Care Unit or ED	4 (1.6)	2 (1.0)	2 (4.8)	

List of abbreviations: LSTs: life-sustaining treatments; ED: emergency department

Prognostic value of the SQ

Table 3 lists the test characteristics of the SQ for death <1 year: sensitivity 89.1% (95%CI 83.9%-93.1%), specificity 40.4% (95%CI 27.0%-54.9%), PPV 84.7% (95%CI 81.5%-87.5%) and NPV 50.0% (95%CI 37.3%-62.8%). Harrell's c-index for the SQ to discriminate patients who died <1 year was 0.56 (95%CI 0.53-0.60).

Addition of other predictors to the SQ

Significant univariable predictors of approaching death are presented in Table 4. The following predictors were significant in multivariable analyses: NS-answer to the SQ (HR 3.16); ≥1 ED-visit in the preceding 6 months (HR 1.70); ECOG performance status 3-4 (HR 2.10); neurologic deterioration or delirium at the ED (HR 11.33). Harrell's c-index for this model including an NS-answer to the SQ was 0.66, and 0.63 without an NS-answer to the SQ. Akaike's information criterion was better in the model with NS-answer to the SQ than in the model without NS-answer to the SQ (2136.317 versus 2154.737, p<0.0001).

In a sub-analysis among the 203 NS-patients, only ECOG performance status 3-4 was predictive of approaching death (HR 2.50; 95%CI 1.88-3.33; p<0.0001). NS-patients with ECOG 3-4 had a HR of 2.45 (95%CI 1.85-3.25; p<0.0001) of approaching death compared to S-patients or NS-patients with ECOG 0-2. Median survival for NS plus ECOG 0-2 was 6.0 months (95%CI 4.7-7.3) and 1.0 month (95%CI 0.6-1.4) for NS-ECOG 3-4 patients.

Test characteristics of the SQ plus ECOG 3-4 for death >1 year were: sensitivity 40.1% (95%CI 33.1%-47.4%), specificity 92.3% (95%CI 81.5%-97.9%), PPV 95.1% (95%CI 88.1%-98.0%) and NPV 29.4% (95%CI 26.6%-32.4%; Table 5). Harrell's c-index for the combination of SQ and ECOG 3-4 to discriminate patients who died <1 year was 0.65 (95%CI 0.62-0.69).

Table 3. Test characteristics of the Surprise Question and Surprise Question plus Poor Performance for screening for palliative care needs in advanced cancer patients visiting the emergency department

	Median survival (95% CI)	**Death <1 year**	**Death >1 year**	**Total**	**Test characteristics**	**% (95% CI)**
Aim: identifying palliative care needs						
SQ					Sensitivity	89.1 (83.9-93.1)
NS	3 months (2.1-3.9)	172	31	203 (82.9%)	Specificity	40.4 (27.0-54.9)
S	9 months (0.8-17.2)	21	21	42 (17.1%)	Positive predictive value	84.7 (81.5-87.5)
Total	3 months (1.8-4.2)	193 (78.8%)	52 (21.2%)	245	Negative predictive value	50.0 (37.3-62.8)
	p<0.0001					

	Median survival (95% CI)	**Death <1 year**	**Death >1 year**	**Total**	**Test characteristics**	**% (95% CI)**
Aim: identifying end-of-life phase						
SQ + ECOG					Sensitivity	40.1 (33.1-47.4)
NS + ECOG 3-4	1 month (0.6-1.4)	77	4	81 (33.2%)	Specificity	92.3 (81.5-97.9)
NS + ECOG 0-2; S	6 months (4.7-7.3)	115	48	163 (66.8%)	Positive predictive value	95.1 (88.1-98.0)
Total	3 months (1.8-4.2)	192 (78.7%)	52 (21.3%)	244	Negative predictive value	29.4 (26.6-32.4)
	p<0.0001					

In the upper part of the table the test performance of the Surprise Question in all 245 patients is displayed. The lower part of the table presents the test performance of the SQ plus the ECOG performance status. For this, patient population is split in two groups: 1) NS-patients (n=203) with an ECOG performance status of 3 or 4, and 2) NS-patients with an ECOG 0-2 or S-patients with any ECOG status. 1 patient had an unknown ECOG performance status and was excluded for this sub-analysis. List of abbreviations: SQ: surprise question; CI: confidence interval; NS: not surprised; S: surprised; ECOG: Eastern Cooperative Oncology Group

Table 4. Predictors of approaching death in 245 patients with advanced cancer visiting the emergency department

	Univariable analysis			**Multivariable analysis**		
Predictors	**HR**	**95% CI**	**P-value**	**HR**	**95% CI**	**P-value**
Surprise Question	2.06	1.44-2.94	<0.0001	3.16	1.75-5.70	<0.0001
Local anti-cancer treatment in preceding 3 months	1.07	0.80-1.42	0.65			NS
Systemic anti-cancer treatment in preceding 3 months	0.69	0.52-0.92	0.010			NS
≥1 ED-visit in the preceding 6 months	1.31	1.00-1.71	0.048	1.70	1.17-2.47	0.006
Home care	1.48	1.02-2.15	0.041			NS
LST discussed and documented	1.66	1.24-2.23	0.001			NS
ECOG 3-4	1.99	1.53-2.61	<0.0001	2.09	1.44-3.05	<0.0001
Neurologic deterioration or delirium	12.39	1.66-92.55	0.014	11.33	1.42-90.68	0.022
Dyspnoea	1.51	1.04-2.19	0.029			NS
Referral for new symptom	0.66	0.49-0.88	0.005			NS
Referral for acute symptom	0.75	0.56-1.01	0.054			NS

Abbreviations: HR: hazard ratio; CI: confidence interval; NS: not significant; ED: emergency department; LST: life-sustaining treatment; ECOG: Eastern Cooperative Oncology Group

DISCUSSION

In our study, the Surprise Question (SQ) identified patients with advanced cancer at the ED with a poor performance status and multiple symptoms. The SQ had a high sensitivity (89.1%) for death within one year for patients in whom attending physicians would not be surprised (NS-patients). NS-patients had a HR of 2.1 for approaching death compared to patients in whom attending physicians would be surprised (S-patients). However, with a Harrell's c-index of 0.56, the SQ discriminates poorly between patients who died within one year or not. Besides the SQ, other predictors for approaching death in patients with advanced cancer visiting the ED were: recent multiple ED-visits, a poor performance status and neurologic deterioration or delirium. In NS-patients, only ECOG performance status 3-4 was predictive of approaching death (HR 2.5). Addition of ECOG 3-4 to the SQ improved specificity (92.3%) at cost of sensitivity (40.1%) in screening for death within one year.

Our study shows that all patients with advanced cancer visiting the ED in the palliative phase of disease have a limited life-expectancy: median survival was three months. This explains our findings of the high sensitivity (89.1%) but poor discriminative ability (c-index 0.56) of the SQ for death within one year after the ED-visit. Our results are in contrast with the meta-analysis by Downar et al.[21] where sensitivity of the SQ was lower than specificity (67% versus 80%, area under the curve 0.83 (95%CI 0.79-0.87)). This is similar to two earlier studies in cancer patients on the performance of the SQ in a general practice stage IV cancer population by Moroni et al.[28] and in an outpatient oncology clinic by Moss et al.[27] Our finding that sensitivity of the SQ was higher at the ED (89.1%) than in the studies by Moroni (70%) and Moss (75%) confirms that patients included in this study had higher a priori risk of death within one year compared to Moroni's and Moss' studies. In addition, it is likely that physicians working in different healthcare settings estimate the SQ differently.[21, 27, 28] In screening for palliative care needs at the ED, identifying as many truly deteriorating patients as possible (hence high sensitivity), is preferred over selecting very accurately who might not benefit from palliative care (high specificity). Specificity may be low in our study, because the ED-visit can also be accompanied with temporary deterioration, in which patients' condition can improve after interventions at the ED. These interventions may encompass improvement of pain medication, start of antibiotics and blood transfusions. A study in the ED-setting in patients with heart failure showed comparable performance of the SQ (sensitivity 79%, specificity 57%), but with a higher c-index (0.68).[35] The poor discriminative ability of the SQ for death within one year indicates that the SQ should not be used as a predictor of one-year-survival; however, with a HR of 2.1 for approaching death in NS-patients (with a median survival of three months) compared to S-patients (with a median survival of nine months), the SQ can identify those who have more urgent palliative care needs.

Downar et al. suggested that the SQ would perform better with addition of other indicators of palliative care needs.[21, 43] We therefore added poor physical performance status (ECOG 3-4), which resulted in increased specificity (from 40% to 92%) at cost of sensitivity (from 89% to 40%). This is probably because most patients visit the ED with problems causing a decreased physical performance (which might improve after the ED-visit), regardless of their prognosis. The high positive predictive value (95.1%) demonstrates that SQ plus ECOG 3-4 is correct in 95% (PPV) in identifying patients who die within the year, with a hazard ratio for approaching death of 2.5. The c-index of SQ plus ECOG 3-4 increased to a moderate 0.65. It may feel obvious that performance status is part of the assessment associated with answering the SQ; however, both the SQ and ECOG 3-4 were independent predictors of approaching death in multivariable analysis. Since addition of ECOG 3-4 improved the SQ's discriminative ability, an NS-answer should be followed by an assessment of the performance status to differentiate between urgency of palliative care needs.

Our study shows that the SQ plus ECOG 3-4 can discern three groups of patients with different levels of urgency for initiating palliative care. Firstly, although S-patients had the longest survival in our study, their median survival was only nine months, indicating that they were likely to already have had palliative care needs before the ED-visit. Therefore, for all patients with advanced cancer, we recommend a two-track approach in which disease-modifying treatment is complemented with palliative care and conversations about patient's wishes to prepare for the last phase of life.[44] Secondly, NS-patients were characterized by a poor performance status with multiple symptoms and a median survival of three months. In these patients, palliative care directed to symptom-management and quality of life should be discussed as soon as possible. Thirdly, NS-patients with ECOG 3-4 had the shortest median survival of only 1 month, indicating that they are in the end-of-life phase. Therefore, in NS plus ECOG 3-4 patients, end-of-life care according to patient's wishes should be initiated immediately.

In our study, it seems that physicians at the ED were able to mark deterioration and futility of treatment in the most vulnerable patients. In 16% of the patients without documented limitations on life-sustaining treatments (LSTs) before the ED-visit, limitations on life-sustaining treatments were documented afterwards. This phenomenon is known as ED-initiated palliative care, in which ED-visits function as 'trigger' to evaluate a patient's health status and situation.[6] Interestingly, all patients in whom LSTs were discussed after the ED-visit were NS-patients, demonstrating that LST-documentation in our hospital was focused on those with the shortest life-expectancy. However, S-patients had a limited survival as well, which means that all patients with advanced cancer can benefit from ED-initiated palliative care.

Strengths and limitations

This prospective study with a long follow-up until February 2019 evaluates the prognostic value of the one-year SQ in patients with advanced cancer visiting the ED. Recall bias of attending physicians answering the SQ and assessing ECOG performance status is possible because e-questionnaires were sent within one working day. After this time period, physicians might regard their patients differently, with possible bias that sicker patients were remembered more likely than those not as sick. As patient and disease characteristics were abstracted from EPRs, under- or over-registration of symptoms is possible; also, physicians might have individual preferences for documenting the main symptom. Since symptoms of the four domains of palliative care are not systematically registered at the ED, this is especially true for psychological, social, and spiritual symptoms. We chose to study the association between indicators of palliative care needs with approaching death rather than with death <1 year, because predictors for approaching death indicate which patients need palliative care most urgently.

Our study shows that the SQ is useful for identifying patients with advanced cancer having palliative care needs at the ED. Since ED-initiated palliative care effectively improves the quality of life of patients, all actions at the ED in NS-patients who, in our study, had a median survival of only three months, should be performed in coherence with appropriate end-of-life care.[10] In practice, this includes goals-of-care conversations and palliative care needs assessments at the ED (e.g., Screen for Palliative and End-of-life care needs in the ED (SPEED)[45] or the shorter 5-SPEED[46]), consultation of a palliative care consultation team and referral to appropriate care at the place preferred by the patient and family.

More knowledge should be obtained about the use of the ’double surprise question‘ at the ED, adding ’Would I be surprised if this patient is still alive after one year?’ after an S-answer. The double surprise question could improve the SQ’s specificity by identifying a third group more associated with frailty and gradual deterioration.[47] The effect of the SQ on the quality of care and whether NS-patients have more palliative care needs than S-patients should be studied.

CONCLUSION

The SQ is useful to screen for patients with advanced cancer having palliative care needs at the ED with a sensitivity of 89% and positive predictive value of 85%. Addition of ECOG performance status 3-4 in NS-patients further differentiates prognosis and urgency of palliative care needs. We recommend using SQ plus ECOG 3-4 at the ED as trigger to start ED-initiated palliative care and goals-of-care conversations to arrange appropriate care according to patient’s wishes.

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CHAPTER 6

Assessment of symptom burden and information needs helps tailoring of palliative care consultations: an observational study

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ABSTRACT

Objective

The objective of this study is to study (1) the relationship between patient-reported symptom burden and information needs in hospital-based palliative care and (2) differences in patient-reported needs during the disease trajectory.

Methods

Observational study: patient-reported symptom burden and information needs were collected via a conversation guide comprising assessment scales for 12 symptoms (0–10), the question which symptom has priority to be solved and a question prompt list on 75 palliative care-related items (35 topics, 40 questions). Non-parametric tests assessed associations.

Results

Conversation guides were used by 266 patients. Median age was 65 years (IQ-range, 57–72), 49% were male and 96% had cancer. Patients reported highest burden for *Fatigue* (median = 7) and *Loss of appetite* (median = 6) and prioritised *Pain* (26%), *Fatigue* (9%) and *Shortness of breath* (9%). Patients wanted information about 1–38 (median = 14) items, mostly *Fatigue* (68%), *Possibilities to manage future symptoms* (68%) and *Possible future symptoms* (67%). Patients also wanted information about symptoms for which they reported low burden. Patients in the symptom-directed phase needed more information about hospice care.

Conclusion

Symptom burden and information needs are related. Patients often also want information about non-prioritised symptoms and other palliative care domains. Tailored information-provision includes inviting patients to also discuss topics they did not consider themselves.

INTRODUCTION

Effective communication between patients, their families and clinicians during the palliative phase of disease is essential to adequately assess and meet physical, psychosocial and spiritual needs, and to set goals of care.[1] However, patients, their family, and clinicians often consider addressing such topics to be difficult.[2] Patients and family often do not know what palliative care entails, what they might need or what to discuss during palliative care consultations.[3, 4] Most patients underreport their symptoms.[5, 6] They often appreciate receiving information about symptoms, prognosis, and about practical, psychosocial, or spiritual issues. These information needs may change over time.[4, 7-9] Clinicians often feel unprepared to discuss end-of-life matters or do not know which topics to address.[2, 10, 11] Research has shown that clinicians tend to underestimate and under-document the severity of symptoms compared to what patients report themselves.[12-14]

Core elements of palliative care consultations are a comprehensive assessment of needs of patients and family, and informing them about (future) symptoms and social, psychological, and existential dimensions of their palliative disease phase. However, palliative care consultations may take up time and patient-reported burden and information needs may change during the disease trajectory, requiring regular assessments. Insight into patient-reported symptom burden and information needs may inform clinicians about how they can tailor palliative care consultations to the needs of patients and family.

Patients can report symptom burden and wellbeing by completing patient-reported outcome measures (PROMs). It is known that individual patients can score symptom burden differently because they experience their problems in many ways, and because symptoms may also have social, psychological or existential aspects.[15, 16] Before initiating symptom management, scores should therefore always be discussed with patients following a multidimensional approach.[17] Another tool that supports palliative care consultations is a question prompt list, i.e., a structured list of sample questions that can help patients and family formulate questions for their consultation.[18]

The primary objective of this study was to determine whether patient-reported symptom burden and prioritised symptoms are related to patients' information needs, using a PROM and a question prompt list. The second objective was to study whether there are any differences in patient-reported symptom burden and information needs between the disease-modifying phase versus symptom-management phase.

METHODS

Setting

This observational study took place at a Dutch academic hospital that includes a Center of Expertise in Palliative Care since 2011 and hosts a palliative care consultation team.[19] This team is available for consultation to all clinical departments that care for adult patients. To support consultations, the team has developed the Leiden Guide on Palliative Care, hereinafter referred to as the *conversation guide*, which encompasses a PROM (the Utrecht Symptom Diary)[20] and a question prompt list to help patients, their families, and clinicians to prepare for consultations. The development of the conversation guide is published elsewhere.[21] The conversation guide is distributed to patients and family before consultations to empower them to ask their questions and collaboratively set the agenda for the consultation. Patients and family are instructed by the palliative care consultant on how to use the conversation guide. Patients could use it alone, or with family. Before providing the conversation guide, the consultants of the palliative care consultation team estimate whether patients and family have sufficient time and energy to use it. They do not give it to patients who are already in the dying phase. Patients and family may refuse to use (parts of) the conversation guide. In 20-25% of all palliative care consultations, the conversation guide is used. Written consent from patients was not required according to Dutch (WGBO, article 458) and European (General Data Protection Regulation) Law. The study was approved by the Medical Ethical Committee of Leiden University Medical Center on 26 April 2019.

Participants and procedures

Patients were included if they had had a consultation with a palliative care consultant, had used a conversation guide between December 2013 and November 2018, and were at least 18 years old. If patients had used a conversation guide multiple times, only the first conversation guide was used for data collection. Two trained research assistants collected data from the conversation guides. Patient characteristics (age, sex, primary diagnosis) and survival in weeks from consultation to death or study closure were taken from electronic patient records. Survival data were updated until 21 January 2021. For all primary diseases, the palliative disease phase (disease-modifying phase or symptom-management phase) was categorised retrospectively from electronic patient records by a palliative care consultant (EJMdN) and a researcher (MV). They used Lynn and Adamson's classification:

- Disease-modifying phase, which focusses on disease treatment for life-prolongation and symptom management;
- Symptom-management phase, in which treatment is aimed at symptom relief or terminal care.[22]

They had consensus meetings about codes that were unclear during data collection.

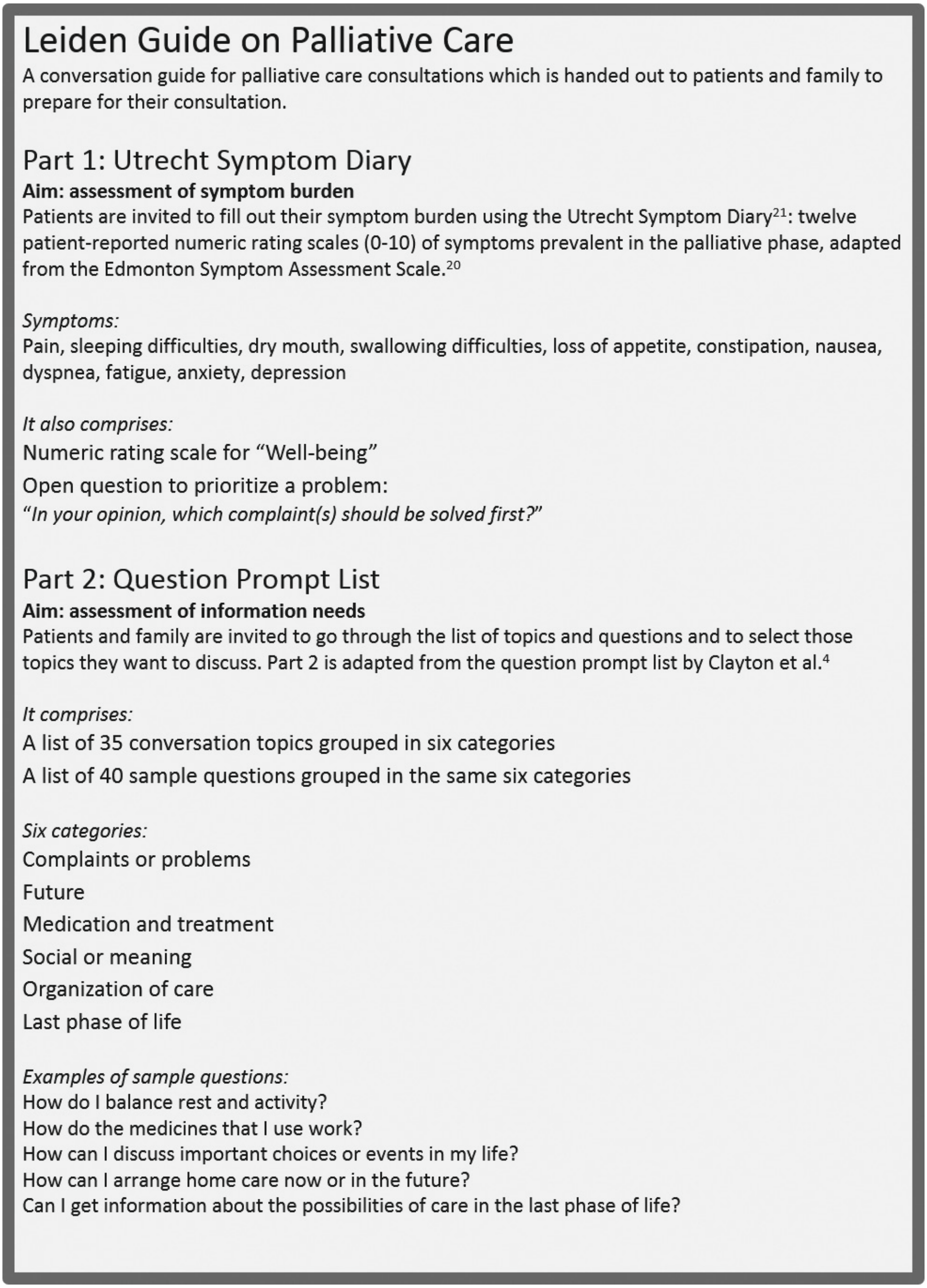
Data collection using the conversation guide: the Leiden Guide on Palliative care

The conversation guide comprises two parts (Figure 1). Part 1 consists of the Utrecht Symptom Diary (USD, an adapted and translated version of the Edmonton Symptom Assessment System, ESAS) and includes twelve 0-10 numeric rating scales (0 = *no symptom burden*; 10 = *worst symptom burden imaginable*) to assess pain, sleeping problems, dry mouth, swallowing problems, loss of appetite, constipation, nausea, shortness of breath, fatigue, anxiety, depression and wellbeing.[20, 23] Patients can prioritise symptoms and problems with the item "*In your opinion, which problem(s) should be solved first?*". The USD is used to monitor burden over time and to assess treatment effects on often-experienced symptoms in the palliative phase. Using the USD, patients can score experienced wellbeing and severity of their symptoms.[12]

Part 2 consists of a question prompt list about palliative care to assess the information needs of the patient and family. The question prompt list was translated from Clayton et al. and adapted, and now consists of 35 conversation topics and 40 sample questions (75 items in total) grouped in six categories (Figure 1 and Supplement 1).[18, 21] Patients are instructed to tick the boxes of the topics and/or questions in the conversation guide they would like to discuss during consultations. The Center of Expertise in Palliative Care keeps duplicates of all conversation guides that patients have used, for purposes of care evaluation. In this study, we collected the data on symptom burden and information needs that patients had reported via the conversation guide.

Analyses

Descriptive statistics were used to describe patient characteristics, patient-reported symptom burden, prioritised symptom(s) and the topics and questions that patients and families selected in the question prompt list. Survival from consultation to death or study closure was calculated using Kaplan-Meier's methodology. We used a log-rank test to compare survival between patients in the disease-modifying phase versus symptom-management phase and rounded up to whole weeks. Symptom burden ratings were analysed both as continuous and as categorial outcomes; for the latter, ratings were classified as mild (rating <4), clinically relevant (burden requiring more comprehensive assessment, rating ≥4), or serious (rating ≥7).[24, 25] Patients could fill in more than one symptom to prioritise; for purposes of analysis, the first four symptoms reported as priorities were included. Also for purposes of analysis we clustered questions from the question prompt list by topic and category (Supplement 2). We assessed the associations between patient-reported symptom burden, prioritised symptom(s), and information needs about symptoms with Chi-square tests, Fisher's exact tests, or and Mann–Whitney U tests (for not-normally distributed continuous variables) as appropriate; these tests were also used to compare patients in the disease-modifying versus symptom-



Leiden Guide on Palliative Care

A conversation guide for palliative care consultations which is handed out to patients and family to prepare for their consultation.

Part 1: Utrecht Symptom Diary

Aim: assessment of symptom burden

Patients are invited to fill out their symptom burden using the Utrecht Symptom Diary[21]: twelve patient-reported numeric rating scales (0-10) of symptoms prevalent in the palliative phase, adapted from the Edmonton Symptom Assessment Scale.[20]

Symptoms:
Pain, sleeping difficulties, dry mouth, swallowing difficulties, loss of appetite, constipation, nausea, dyspnea, fatigue, anxiety, depression

It also comprises:

Numeric rating scale for "Well-being"

Open question to prioritize a problem:
"*In your opinion, which complaint(s) should be solved first?*"

Part 2: Question Prompt List

Aim: assessment of information needs

Patients and family are invited to go through the list of topics and questions and to select those topics they want to discuss. Part 2 is adapted from the question prompt list by Clayton et al.[4]

It comprises:

A list of 35 conversation topics grouped in six categories

A list of 40 sample questions grouped in the same six categories

Six categories:

Complaints or problems

Future

Medication and treatment

Social or meaning

Organization of care

Last phase of life

Examples of sample questions:
How do I balance rest and activity?
How do the medicines that I use work?
How can I discuss important choices or events in my life?
How can I arrange home care now or in the future?
Can I get information about the possibilities of care in the last phase of life?

Fig. 1. Outline of the conversation guide (Leiden Guide on Palliative care) used for data collection.

management phase by characteristics, symptom burden, prioritised symptom(s), and information needs. For analyses using data from both the USD and the question prompt list, patients who had not used either were excluded. Associations between disease phase and topics included in the question prompt list that were <0.01 were regarded as statistically significant.

RESULTS

From December 2013 to October 2018, 1,485 patients were referred to the palliative care consultation team. Table 1 lists the characteristics of all 321 patients who filled in the conversation guide were included; 266 (83%) patients filled in both parts. The median age was 65 years (IQ-range, 57-72), 49% were male and most patients had cancer (96%). Median survival from consultation was 7 weeks (IQ-range: 2-26).

Reported symptom burden and prioritised symptom(s)

Patient-reported symptom burden is presented in Table 2. Patients reported the highest median burden for *Fatigue*, *Loss of appetite*, *Dry mouth,* and *Constipation*. Patients reported a median of six symptoms (IQ-range: 4-8) with clinically relevant burden, and a median of three symptoms (IQ-range 1-5) with serious burden, most often *Fatigue*, *Loss of appetite* and *Dry mouth*. Seventy per cent of the patients reported clinically relevant burden related to *Well-being*. Patients in the symptom-management phase versus disease-modifying phase reported higher burden for *Loss of appetite* (median=7 vs. 5, p=0.010) and lower burden for *Anxiety* (median=2 vs. 3, p=0.030; Table 3). Overall, patients most often prioritised *Pain*, *Fatigue* and *Shortness of breath*. Regardless of the particular symptom, the higher the patient-reported symptom burden, the more often patients indicated that the symptom in question should be prioritised.

Information needs

Table 4 lists the topics patients selected in the question prompt list. Patients selected a median of five out of six categories (range 1-6) and of 14 out of 75 items (range 1-38) to discuss. The category *Symptoms/problems* was selected most often and *Social/meaning* least often. The top five selected topics were *Fatigue*, *Treatment options for future symptoms*, *Expected future symptoms*, *Pain* and *Home care*. The five least selected topics were *Sexuality and intimacy*, *Volunteers*, *Medication intake times*, *Meaning/philosophy of life* and *Next steps regarding medication*. Patients in the symptom-management phase versus disease-modifying phase more often selected *Hospice care* and less often selected *Sexuality and intimacy*.

Table 1. Characteristics of 321 patients who filled out the Utrecht Symptom Diary in the Leiden Guide on Palliative Care.

	Total population		**Disease-modifying phase**		**Symptom-management phase**		
Patient characteristics	**n**	**(% of 321)**	**n**	**(% of 140)**	**n**	**(% of 181)**	**P-value**
Male gender	158	(49.2)	63	(45.0)	95	(52.5)	0.18
Age in years, median (IQ-range)	65	(57-72)	63	(52-70)	68	(60-73)	<0.0001
Diagnosis							
Cancer (per anatomic region)	*307*	*(95.6)*	*136*	*(97.1)*	*171*	*(94.5)*	*0.24*
Gastro-intestinal	100	(31.2)	39	(78.1)	61	(33.7)	
Gynaecological	42	(13.1)	18	(12.9)	24	(13.3)	
Respiratory	41	(12.8)	20	(14.3)	21	(11.6)	
Soft tissue	31	(9.7)	15	(10.7)	16	(8.8)	
Urological	22	(6.9)	8	(5.7)	14	(7.7)	
Head-neck	19	(5.9)	6	(4.3)	13	(7.2)	
Melanoma	17	(5.3)	13	(9.3)	4	(2.2)	
Haematological	13	(4.0)	6	(4.3)	7	(3.9)	
Breast	11	(3.4)	5	(3.6)	6	(3.3)	
Unknown primary	3	(0.9)	1	(0.7)	2	(1.1)	
Neurological	2	(0.6)	2	(1.4)	0	(0.0)	
Other	6	(1.9)	3	(2.1)	3	(1.7)	
Non-cancer	*14*	*(4.4)*	*4*	*(2.9)*	*10*	*(5.5)*	*0.24*
End-stage renal failure	4	(1.2)	2	(1.4)	2	(1.1)	
Pulmonal failure†	4	(1.2)	2	(1.4)	2	(1.1)	
Neurological deterioration‡	3	(0.9)	0	(0.0)	3	(1.7)	
Cardiovascular§	1	(0.3)	0	(0.0)	1	(0.5)	
Other¶	1	(0.3)	0	(0.0)	1	(0.5)	
Survival in weeks, median (IQ-range)	7	(2-26)	12	(5-54)	5.0	(-13)	<0.0001

Disease-modifying phase and symptom-management phase are classified using Lynn and Adamson's definitions: disease-modifying phase, which focusses on disease treatment for life-prolongation and symptom management; symptom-management phase, in which treatment is aimed at symptom relief or terminal care.[22]

† *Diagnoses: chronic obstructive pulmonary disease; lung fibrosis; combined restrictive/obstructive pulmonary disease due to bronchiectasis; interstitial lung disease*

‡ *Diagnoses: amyotrophic lateral sclerosis; Parkinson's disease; post-anoxic encephalopathy*

§ *Diagnoses: right-sided heart failure; aortic dissection*

¶ *Diagnosis: persistent ileus of the small intestine*

List of abbreviations: IQ-range: interquartile range

Table 2. Patients-reported symptom burden assessed with the Utrecht Symptom Diary (n=321).

	Score		**Score ≥4†**		**Score ≥7†**		**Priority‡**	
Utrecht Symptom Diary item	**Median**	**(IQ-range)**	**n**	**(% of 321)**	**n**	**(% of 321)**	**n**	**(% of 321)**
Pain	4	(1-6)	159	(49.5)	65	(20.2)	82	(25.5)
Sleeping problems	4	(1-7)	165	(51.4)	95	(29.6)	15	(4.7)
Dry mouth	5	(2-8)	198	(61.7)	113	(35.2)	12	(3.7)
Swallowing problems	1	(0-4)	90	(28.0)	49	(15.3)	9	(2.8)
Loss of appetite	6	(3-9)	209	(65.1)	139	(43.3)	15	(4.7)
Constipation	5	(2-7)	182	(56.7)	90	(28.0)	12	(3.7)
Nausea	0	(0-3)	73	(22.7)	35	(10.9)	21	(6.5)
Shortness of breath	1	(0-5)	110	(34.3)	48	(15.0)	28	(8.7)
Fatigue	7	(4-8)	242	(75.4)	157	(48.9)	29	(9.0)
Anxiety	2	(0-5)	115	(35.8)	62	(19.3)	17	(5.3)
Depression	3	(0-6)	133	(41.4)	63	(19.6)	12	(3.7)
Well-being§	5	(4-7)	224	(69.8)	88	(27.4)	0	

† *Patient-reported symptom burden scores of ≥4 are considered as clinically relevant burden; ≥7 as serious burden. In this table, both percentages are reported per symptom. Totals of rows may therefore exceed 100%. Results of scores <4 are not presented in this table.*
‡ *106 patients did not indicate which symptom they want to be solved first. Patients could fill in more than one symptom; for purposes of analysis, the first four symptoms reported as priority were included in the analyses. Symptoms are in the same order as in the Utrecht Symptom Diary and are scored on a scale from 0 to 10.*
§ *A higher score indicates poorer well-being; "Well-being" is never prioritised by any patient.*
List of abbreviations: IQ-range: interquartile range

Table 3. Differences in patient-reported symptom burden in 140 patients in the disease-modifying phase versus 181 patients in the symptom-management phase.

	Disease-modifying phase (n=140)		**Symptom-management phase (n=181)**		
Utrecht Symptom Diary item	**Median**	**(IQ-range)**	**Median**	**(IQ-range)**	**P-value**
Pain	3	(1-6)	4	(2-6)	0.13
Sleeping problems	4	(1-6)	5	(1-7)	0.15
Dry mouth	5	(1-7)	5	(2-8)	0.12
Swallowing problems	1	(0-3)	1	(0-5)	0.47
Loss of appetite	5	(1-8)	7	(4-9)	0.010
Constipation	5	(1-7)	5	(3-7)	0.24
Nausea	0	(0-4)	1	(0-3)	0.13
Shortness of breath	1	(0-4)	2	(0-5)	0.07
Fatigue	6	(4-8)	7	(4-9)	0.12
Anxiety	3	(0-6)	2	(2-5)	0.030
Depression	3	(1-6)	2	(0-6)	0.70
Well-being†	5	(3-7)	5	(4-7)	0.50

Disease-modifying phase and symptom-management phase are classified using Lynn and Adamson's definitions: disease-modifying phase, which focusses on disease treatment for life-prolongation and symptom management; symptom-management phase, in which treatment is aimed at symptom relief or terminal care.[22]
Symptoms are in the same order as in the Utrecht Symptom Diary and are scored on a scale from 0 to 10.
List of abbreviations: IQ-range: interquartile range
† *A higher score indicates poorer well-being; "Well-being" is never prioritised by any patient.*

Table 4. Topics patients (n=266) selected to discuss during consultations with help of a question prompt list.

	Total population n=266		Disease-modifying phase	Symptom-management phase	
Topic	**n**	**%**	**% (n=118)**	**% (n=148)**	**P-value†**
Category 1: Symptoms/problems	**250**	**94.0**	**94.1**	**93.9**	**0.96**
Pain	159	59.8	51.7	66.2	0.017
Dry mouth	78	29.3	24.6	32.9	0.13
Loss of appetite	147	55.3	55.1	55.4	0.96
Constipation	69	25.9	23.7	27.7	0.46
Nausea	66	24.8	18.6	29.7	0.039
Shortness of breath	74	27.8	20.3	33.8	0.016
Fatigue	181	68.0	68.6	67.6	0.85
Anxiety	96	36.1	39.0	33.8	0.38
Depression	88	33.1	37.3	29.7	0.19
Nutrition	82	30.8	33.1	29.1	0.48
Sexuality and intimacy	13	4.9	10.2	0.7	0.007
Category 2: Future	**188**	**70.7**	**73.7**	**68.2**	**0.77**
Expected future symptoms	179	67.3	70.3	64.9	0.35
Treatment options for future symptoms	181	68.0	70.3	66.2	0.47
Category 3: Medication and treatment	**215**	**80.8**	**81.4**	**80.4**	**0.85**
Side effects of medication	80	30.1	29.7	30.4	0.90
Medication intake times	46	17.3	19.5	15.5	0.40
Next steps regarding medication	51	19.2	13.6	23.6	0.040
Medication for when I suddenly have more symptoms	99	37.2	33.1	40.1	0.21
Types of morphine-like medication	120	45.1	38.1	50.7	0.042
Choice between treatment/no treatment of the disease	105	39.5	42.4	37.2	0.39
Choice between treatment and quality of life	138	51.9	60.2	45.3	0.016
Category 4: Social/meaning	**138**	**51.9**	**58.5**	**46.6**	**0.06**
Support or information for my children	73	27.4	31.4	24.3	0.20
Support or information for the people around me	100	37.6	39.0	36.5	0.68
Meaning/philosophy of life	47	17.7	18.6	16.9	0.71
Category 5: Organisation of care	**210**	**78.9**	**73.7**	**83.1**	**0.06**
Home care	151	56.8	50.0	62.2	0.047
Domestic care	103	38.7	36.4	40.5	0.50
Hospice care	64	24.1	14.4	31.8	0.001
Volunteers	37	13.9	10.2	16.9	0.12
Point of contact for symptoms	122	45.9	44.1	47.3	0.60
Role of the general practitioner	129	48.5	48.3	48.6	0.96
Possibilities of care	125	47.0	47.5	46.6	0.89

Table 4. *(continued)*	**Total population**		**Disease-modifying phase**	**Symptom-management phase**	
Category 6: Last phase of life	**197**	**74.1**	**69.5**	**77.7**	**0.13**
Palliative sedation	147	55.3	54.2	56.1	0.76
Euthanasia	147	55.3	55.1	55.4	0.96
Foods and fluids	82	30.8	28.8	32.4	0.53
Practical matters relating to the end of life	149	56.0	50.8	60.1	0.13
Course of last phase of life	114	42.9	40.7	44.6	0.52

This table shows how often patients selected the topics for discussion with the help of a question prompt list. The categories and topics are ordered similar to the question prompt list. See Supplement 2 for the code book that was used to group topics and questions of the question prompt list. Disease-modifying phase and symptom-management phase are classified using Lynn and Adamson's definitions: disease-modifying phase, which focusses on disease treatment for life-prolongation and symptom management; symptom-management phase, in which treatment is aimed at symptom relief or terminal care.[22]

† *This p-value represents the statistical differences in information needs between disease-modifying phase versus symptom-management phase. P-values of <0.01 were considered statistically significant.*

Relationship between symptom burden and prioritised symptom(s) with information needs

Patients had more information needs regarding symptoms they reported as conferring a serious or clinically relevant burden or had prioritised (Table 5). *Pain* and *Fatigue* were symptoms on which patients scored ≥4 and most often wanted information about. Mild symptoms (score <4) about which patients most frequently wanted information were *Fatigue* and *Loss of appetite*.

DISCUSSION

This study aimed to describe the relationship between patients' symptom burden and information needs and to assess the relationship between those. Patients wanted information about the symptoms for which they reported clinically relevant burden but also about symptoms for which they reported mild burden. In general, patients had information needs about a wide range of topics; these mostly concerned current and future symptoms and symptom management. The need for information about sexuality and intimacy came last on the list of patients and families, especially when the disease was in the symptom-management phase. In that phase, patients often needed information about hospice care.

Symptom burden and prioritised symptom(s)

Patients in our study reported the highest symptom burden for *Fatigue* and *Loss of appetite*, which corresponds with the findings in a study on patients with advanced cancer

Table 5. Relationship between symptom burden and information needs of patients in the palliative phase (n=266)

	Symptom burden <4			**Symptom burden ≥4†**			**Symptom burden ≥7†**			**Prioritised symptom‡**		
Utrecht Symptom Diary item	**Total <4 n**	**Information needs n**	**(% of 266)**	**Total ≥4 n**	**Information needs n**	**(% of 266)**	**Total ≥7 n**	**Information needs n**	**(% of 266)**	**Total prioritised n**	**Information needs n**	**(%)**
Pain	116	39	(33.6)	139	109	(78.4)	55	45	(81.5)	70	61	(87.1)
Dry mouth	100	4	(4.0)	156	71	(45.5)	88	52	(59.0)	10	10	(100)
Loss of appetite	74	25	(33.8)	173	113	(65.3)	115	78	(67.8)	14	14	(100)
Constipation	91	11	(12.1)	155	51	(32.9)	75	36	(48.0)	10	7	(70.0)
Nausea	194	24	(12.4)	65	40	(61.5)	30	23	(76.7)	18	16	(88.9)
Shortness of breath	169	17	(10.1)	87	51	(58.6)	36	27	(75.0)	87	51	(58.6)
Fatigue	57	25	(43.9)	201	149	(74.1)	129	103	(79.8)	23	22	(95.7)
Anxiety	156	21	(13.5)	99	68	(68.7)	56	44	(78.6)	17	17	(100)
Depression	134	18	(13.4)	114	64	(56.1)	56	41	(73.2)	12	12	(100)

This table depicts the proportion of patients having information needs about the symptom with a score of <4; ≥4 or ≥7 respectively, and symptoms the patient prioritised. Total patients included 266; 45 patients were excluded because they did not fill out the question prompt list. Not all patients completed the assessment scales for all symptoms. Symptoms are in the same order as in the Utrecht Symptom Diary and are scored on a scale from 0 to 10.

"Sleeping problems", "Swallowing problems" and "General wellbeing" are part of the Utrecht Symptom Diary, but do not have a corresponding item in the question prompt list and are therefore not part of this table.

† Symptom burden and prioritised symptoms were statistically significantly associated with more information needs. P-values of <0.05 were considered statistically significant. Symptom burden ≥4 also includes the patients who reported symptom burden ≥7.

‡ 177 patients (66.5%) reported symptoms they wanted to prioritise and had used the question prompt list; there was room to report more than one symptom. For purposes of analysis, the first four prioritised symptoms were included in this analysis.

in the last six months of life, and a systematic review among patients with incurable cancer.[26, 27] The high percentage of patients in the palliative phase with clinically relevant burden from having a dry mouth was also reported in study among UK hospice patients.[28] Our patients most often prioritised *Pain*, *Fatigue* and *Shortness of breath*, even though these did not always cause the highest burden. This is in line with previous studies on how patients prioritise symptoms and suggests that patient-reported symptom burden does not fully reflect symptom experience.[15, 16] Also, in hospital care, there may be more focus on physical symptom burden compared to symptom burden in other dimensions (psychological, social, and existential), influencing the symptoms patients may worry about. Moreover, patients may not be aware that some symptoms, such as a dry mouth, are treatable or occur frequently in the palliative phase. Additionally, pain, fatigue, and shortness of breath significantly impact daily life, and patients and family may fear the occurrence of these symptoms, which might explain why they prioritised them.[15]

Anxiety was reported to be more severe among patients in the disease-modifying phase than those in the symptom-management phase. The difference may be small, but according to Hui et al. a difference in burden of ≥1 is clinically relevant.[30] This difference may be due to a difference in situational anxiety: patients in the disease-modifying phase may experience more anxiety caused by uncertainties associated with life-prolonging treatment and what the future will look like, whereas patients in the symptom-management phase have had more time to deal with their situation, and have more certainty about their prognosis. Additionally, there may be a difference in organic anxiety, which entails somatic causes of anxiety such as side effects of treatment.[31] Zweers et al. found that experienced anxiety may be associated with having accepted that disease-modifying treatment is not an option anymore.[32]

Since Utrecht Symptom Diary symptoms are often multidimensional problems, discussion about these symptoms should extend to psychological distress, social impact and existential aspects to foster optimal care. We hypothesise that patients and families may also worry about symptoms that they associate with death approaching, such as pain and shortness of breath. Clinicians should therefore discuss not only symptom scores, but also possible future symptoms to tailor information-provision.[17] A study in hospice patients demonstrated that although patients scored “0” on the anxiety scale using the Utrecht Symptom Diary, they still may experience tension, or worries.[32] Using a question prompt list in addition to symptom assessment may support a more comprehensive symptom assessment by adding information about the symptoms patients and family worry about. Having a comprehensive insight into symptoms, information needs, and wishes helps to support them better.

Information needs

Patients most often reported information needs related to *Symptoms/problems*, *Medication and treatment* and *Organisation of care*. Least needs for information concern topics about *Social/Meaning*. Patients and families are known to expect clinicians to provide information about their illness, symptoms, care, and future. They expect to discuss social or spiritual support among themselves or with a social worker or spiritual carer.[33] Few patients reported information needs regarding *Sexuality and intimacy*. In a previous study, it was shown that neither patients nor clinicians initiated this topic during consultations.[21] This may be because of time limitations, other priorities, or considering the topic taboo. Additionally, patients find that healthcare professionals generally focus on medical treatment and checking physical symptoms.[34] Yet, in a study on the impact of disease on sexuality and intimacy in patients receiving palliative care, almost half of the patients reported that their intimacy was impacted by their illness, and over 75% of the patients thought discussing intimacy can be helpful.[35, 36] It is likely that, even if the question prompt list explicitly gives them this option, patients do not want or expect to discuss the topic during a palliative care consultation. They may need a more encouraging invitation than a question prompt list to start this particular conversation. In the used version of the question prompt list, the word “sexuality” was placed before “intimacy”. We have reversed it to make it more inviting to discuss non-sexual physical contact with loved ones.

We found that information needs of patients depend on the palliative disease phase. Patients in the symptom-management phase had more information needs about *Hospice care* than patients in the disease-modifying phase. A possible explanation is that the former have fewer treatments or contacts in the hospital and need to organise care in a hospice.

Relationship between symptom burden, prioritised symptom(s), and information needs

We found that patient-reported symptom burden and prioritised symptoms were positively associated with information needs. In addition, patients who reported mild symptom burden often reported information needs on these symptoms. This suggests that symptom scores alone are not fully indicative of patients’ information needs regarding symptoms. For example, concerns about future symptoms or experience with symptoms in others may prompt a wish for information. Using a question prompt list to support patients and families to prepare for palliative care consultations can close the gap between concerns and actual symptom burden, because it encourages patients and families to ask more questions during consultations, and improves understanding of treatment plans and recall of information.[21, 37] Additionally, clinicians of patients who used a question prompt list expressed more engagement with the patient, explained more about prognoses and treatment, responded more to emotions, and were reminded to pay more attention to topics patients wanted to discuss.[21, 38-41]

Strengths and weaknesses

To our knowledge, this is the first study to explore the relationship between symptom burden and information needs, and the differences between patients in the disease-modifying phase versus symptom-management phase, referred to a hospital-based palliative care team. The results of this study may not apply to all patient populations referred to hospital-based palliative care, because it was conducted in an academic medical centre and almost all patients had cancer. The palliative care consultant assesses whether a patient is fit enough to go through the conversation guide, excluding patients in the dying phase. Therefore, this study does not report on symptom burden and information needs of these patients and their families. Patients reported their symptom burden and information needs at the same time. The fact that symptom burden was assessed first in the conversation guide, followed by information needs, may have influenced reported information needs about symptoms; these information needs may have been less had the order been reversed. Since patients and families received only one conversation guide before the consultation, it was not possible to distinguish patient from family needs. However, the information needs of both are relevant in palliative care consultations. The data, although collected some years ago, are still relevant because information provision by clinicians has not changed substantially.

Further research

Our study was conducted among patients of a specialist palliative care team at an academic hospital. In future research, symptom burden and information needs should be assessed in other settings and among patients with a non-cancer diagnosis. Ways to address intimacy and sexuality in palliative care could be further explored. We did not study if patient-reported symptom burden and information needs altered over time, which would be an interesting topic for further research. Future research could study the effect of using a symptom assessment scale combined with a question prompt list on quality of life and person-centred care. This study was conducted using an observational study design in patients who have used the conversation guide. More precise insight into the symptom burden and information needs of patients in palliative care in several care settings can be provided by using a prospective follow-up design in a cohort of patients who have all received the conversation guide. Additionally, reasons for (not) using the conversation guide can be tracked. Also, the use of the conversation guide in the dying phase in identifying the needs of family of patients can be studied.

CONCLUSION

Symptom burden and information needs in the palliative phase are related. However, patients often also have information needs in other domains of palliative care. The use of a conversation guide comprising a symptom assessment scale and a question prompt list can identify patient concerns about current and future symptoms and thus support tailoring of consultations and appropriate care.

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Conflict of interest
All authors declare no conflict of interest.

Data availability statement
Research data are not shared.

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SUPPLEMENTARY MATERIALS

Supplement 1

Question prompt list of the Leiden Guide on Palliative Care 2015.

OVERVIEW OF
POSSIBLE CONVERSATION TOPICS
AND QUESTIONS

LUMC

Center of Expertise in Palliative Care

During the consultation I want to talk about:

Symptoms /problems
- ☐ Pain
- ☐ Constipation (problems with bowel movement)
- ☐ Shortness of breath
- ☐ Nausea
- ☐ Loss of appetite
- ☐ Fatigue
- ☐ Dry mouth
- ☐ Nutrition
- ☐ Anxiety
- ☐ Depression
- ☐ Sexuality and intimacy

Future
- ☐ Expected future symptoms
- ☐ Treatment options for future symptoms

Medication and treatment
- ☐ Side effects of medication
- ☐ Medication intake times
- ☐ Next steps regarding medication
- ☐ Medication for when I suddenly have more symptoms
- ☐ Types of morphine-like medication
- ☐ Choice between treatment/no treatment of the disease
- ☐ Choice between treatment and quality of life

Social/ Meaning
- ☐ Support or information for my children
- ☐ Support or information for the people around me (informal caregivers)
- ☐ Meaning of life / philosophy of life

Organisation of care
- ☐ Home care
- ☐ Domestic care
- ☐ Hospice care
- ☐ Volunteers
- ☐ Point of contact for symptoms (who do I call for what)
- ☐ Role of the GP
- ☐ Possibilities of care

Last phase of life
- ☐ Palliative sedation
- ☐ Euthanasia
- ☐ Food and fluids
- ☐ Practical matters relating to end of life
- ☐ Course of last phase of life

My personal questions
- ☐ ....
- ☐ ....
- ☐ ....

Example questions:

Symptoms/problems

☐ When I have symptoms, what can be done to reduce them?
☐ What can I do myself to reduce my symptoms?
☐ How can I achieve the best possible quality of life with my symptoms?
☐ I am very tired, how do I deal with this?
☐ How do I balance rest and activity?
☐ What can I do to stay fit?
☐ How can I continue to do the things that are important to me?
☐ What is the best food for me to eat?
☐ What can I do to increase my appetite for food?
☐ How can I reduce my pain?
☐ I feel less like having sex or cuddling, how do I deal with this?
☐ Who can help me with feelings of depression and anxiety?
☐ Where do I find reliable information, websites or information leaflets?

Future

☐ What symptoms can I expect in the future and what can I do about them?
☐ Will I have pain?
☐ Will my pain and other symptoms also be treatable in the future?

Social/ Meaning

☐ Where can I find good support/counselling for my children?
☐ Are there any good websites for (young) children?
☐ Which sites/organisations can help my family and friends (family caregivers)?
☐ How can I discuss important choices/events in my life?
☐ How do I find a way of saying goodbye that is right for me?
☐ My views on the meaning of life and on life after death are changing. How do I deal with this?

Organisation of care

☐ How can I arrange home care or domestic help now or in the future?
☐ What can volunteers do for me?
☐ Who do I call for what symptom?
☐ Can I get help with an activity, travel or outing?

Medication and treatment

☐ Are there any other painkillers for me?
☐ How do the medications that I am taking work?
☐ What are the side effects of the medications I am taking?
☐ What are the chances that I will experience side effects?
☐ What can be done about side effects?
☐ How and when should I take my medication?
☐ If I am taking morphine (or a morphine-like medication), can I:
  o become addicted, so it doesn't work anymore or I need more and more of it?
  o stop taking it when my pain is gone?
  o get sleepy or confused?
  o drive a car?
  o become nauseous or constipated (difficult or no bowel movement)?
☐ What does treatment of the disease do to my quality of life?
☐ What are the options if I decide against further treatment of the disease (for example, if I stop chemotherapy)?

Last phase of life

☐ Can I get information about the last weeks of life?
☐ Can I get information about palliative sedation or euthanasia?
☐ How do I manage food and fluids during illness or end of life?
☐ Can I get information about the care options in the last phase of life?
☐ What are the costs of care (for example, home care/hospice)?

Personal questions:

☐ ………
☐ ………
☐ ………
☐ ………
☐ ………
☐ ………
☐ ………

Supplement 2

Table. Classification of categories, topics, and questions of the question prompt list of the Leiden Guide on Palliative Care.

Topic prompt list	Question prompt list	
Category: Complaints or problems		
N/A	1	If I have symptoms, what can be done to improve them?[a]
	2	What can I do myself to reduce my symptoms?[b]
	2b	What are the different options available for controlling my symptoms?[c]
	3	How do I achieve the highest possible quality of life with my symptoms?[d]
	7	How can I still do the things that are important to me?[e]
	13	Where can I find reliable information, websites or flyers?[f]
Pain	10	How can I reduce pain?[g]
	10a	Can you help me reduce my pain?[g]
	10b	What else can I do myself to reduce the pain?[h]
Constipation	*N/A*	-
Shortness of breath	*N/A*	-
Nausea	*N/A*	-
Less appetite	8	What kind of food should I eat?
	9	What can I do to get more appetite for food?[i]
Fatigue	4	I am very tired, how do I deal with this?[j]
	5	How much activity or exercise is too much and how much is too little?
	4_5	I am very tired; how do I deal with rest and activities?[k]
	6	What can I do to stay in shape?[l]
Anxiety	12	Who can help me with depression and anxiety?[m]
	12	Who can help me with depression and anxiety?[m]
Dry mouth	*N/A*	-
Nutrition	*N/A*	-
Sexuality and intimacy	11	I don't feel like having sex or cuddling, how do I deal with this?[n]
Future		
Complaints expected for the future	14	What symptoms may occur in the future and what should I do if they arise?
	15	Will I be in pain?
Possibilities for managing complaints in the future	16	Will my pain and other symptoms be controlled in the future?

Table. Classification of categories, topics, and questions of the question prompt list of the Leiden Guide on Palliative Care. (continued)

Topic prompt list	**Question prompt list**	
Medication and treatment		
N/A	27	Are there other painkillers or alternatives available?
	28	What are all my tablets for?
Side effects of medication	29	What side effects do the medicines I use have?[o]
	30	What is the chance that I will get side effects?[o]
	31	What can be done about side effects?
Medication intake times	32	How and when should I take my medication?
Next steps medication	*N/A*	-
Medication for when I suddenly get more complaints	*N/A*	-
Types of morphine-like medication	33	If I use morphine (or a morphine-like medicine), can I:[p] – become addicted, so it no longer works, or I need more and more? – stop taking it if my pain goes away? – get sleepy or confused? – drive? – get nauseous or constipated (difficulty or unable to defecate)?*
Choice of whether or not to treat the disease	35	What can be done if I choose not to treat the disease anymore (for example if I stop taking chemotherapy)?[q]
Choice between treatment and quality of life	34	What does the treatment of the disease do to my quality of life?[z]
Social or meaning		
N/A	20	How can I discuss important choices / events in my life?[r]
	21	How do I find a way of saying goodbye that suits me?[z]
Help or information for my children	17	Where can I find good help / guidance for my children?[s]
	18	Are there good websites for (young) children?[z]
Help or information for the people around me	19	Which websites / organizations can help my family and friends (caregivers)?[s]
Meaning or philosophy of life	22	My view of the meaning of life and about life after death is changing. How do I deal with this?[z]

Table. Classification of categories, topics, and questions of the question prompt list of the Leiden Guide on Palliative Care. (continued)

Topic prompt list	Question prompt list	
Organization of care		
Home care	23	How can I arrange home care or household care now or in the future?[t]
	23a	How can I arrange home care now or in the future?[t]
Household care	23	How can I arrange home care or household care now or in the future?[t]
	23b	How can I arrange household care now or in the future?[t]
Hospice care	*N/A*	-
Volunteers	24	Are there any volunteers available to help me? (e.g. to take me to an appointment or to do the shopping)
Point of contact for symptoms	25	Who do I call in case of symptoms?[u]
Role of the general practitioner	*N/A*	-
Possibilities of care	26	Can I get help with an activity, travel or trip?[v]
Last phase of life		
Palliative sedation	37	Can I get information about palliative sedation or euthanasia?[w]
Euthanasia	37	Can I get information about palliative sedation or euthanasia?[w]
Fluids and nutrition	38	How do I deal with fluid and nutrition in the event of illness or the end of life?[z]
Practical matters of the end of life	39	Can I get information about the possibilities of care in the last phase of life?
	40	What are the costs of care (for example home care / hospice)?[x]
Course of the last phase of life	36	Can I get information about the last weeks of life?*[y]

List of abbreviations: N/A: not applicable.
Legends:
Because the topic prompt list and question prompt list were separately presented in the Leiden Guide on Palliative Care, the above depicted classification was made to report how often categories and topics were indicated. Some questions did not belong to one specific topic. Topics could be grouped with more than one question and to zero questions.
a-z: adaptations made to the question prompt list (see below)

Construction of the question prompt list

The Center of Expertise Palliative Care of Leiden University Medical Center constructed a Dutch version of Clayton et al.'s question prompt list (QPL) on palliative care in 2013. In team meetings with the palliative care consultants, it was concluded that the QPL needed practical, cultural and organizational adaptations. The QPL consisted of 35 topics and 40 questions in 6 categories. The QPL became part of a conversation guide, the Leiden Guide on Palliative Care, which also included the Utrecht Symptom Diary for assessing symptom burden on symptom assessment scales.

1. Practical:

a. Palliative care consultants estimated that many of their patients would lack energy and time to view all questions in Clayton et al.'s QPL. Therefore, they selected the most important questions and formulated a topic prompt list consisting of all relevant topics, which preceded the list with questions. Questions on "Spiritual and Cultural support" were left out.
b. Questions about symptoms were specified for each symptom, because these would support the symptom assessment scales that the palliative care consultants also used as part of their consultations.
c. Patients often asked questions about the truths and falsehoods about morphine and morphine-like medication, thus questions about this topic were made more specific.
d. Questions for family were excluded in this first version, because palliative care consultants focused primarily on the patient.
e. The palliative care consultation team already used a folder containing information sources (flyers, leaflets and websites), which they could hand out to patients and family during consultations.
f. Contact details of the palliative care consultation team were not a part of the QPL because they had their own business card to hand out.

2. Cultural:

a. Some questions were formulated more directly, which many Dutch people are used to.
b. Personal autonomy is a highly respected principle in the Netherlands; some questions were therefore formulated in such way that patients can maintain self-control.

3. Organizational:

a. In the Netherlands, palliative care consultants are often consulted to get their advice, and do not have the role of co-practitioners. They therefore do not actively participate in decisions about the treatment of the patient's disease.
b. The aim of a palliative care consultation is to empower patients and family and to improve self-management. The formulation of some questions in Clayton et al.'s QPL was changed into a more active form, so that the patient can ask what he or she can do or organize care.
c. Palliative care is covered by Dutch insurance companies, so questions about financial support were omitted.

Adaptations made to the question prompt list

[a] The original question in Clayton et al. is: "*If I have symptoms, what can be done to improve them? (e.g. pain or discomfort, constipation, shortness of breath, nausea or feeling sick, lack of appetite, tiredness, dry mouth)*". The Center of Expertise Palliative Care experienced that patients would rather have the question divided into one question for each symptom.

b The original questions in Clayton et al. are: "Can you help to control my pain?" and "Can you help to control my other symptoms?". See 2a: this question was formulated more directly.

c The original questions in Clayton et al. are: "Can you help me to control my other symptoms?" and "What are the different options available for controlling my pain?" See 2a: this question was formulated more directly.

d The original question in Clayton et al. is: "How can I make the most of my life?" See 1b: the relation to symptoms was added to the formulation of the question.

e The original question in Clayton et al. is: "What can I expect to be able to do?"

f The original questions in Clayton et al. are: "What information is available about palliative care and my illness?" and "Are books, videos or pamphlets available?" See 2b and 3b: these questions were formulated as one question to support self-management of patients and family.

g The original question in Clayton et al. is: "Can you help to control my pain?" See 2b and 3b: this question was re-formulated to support self-management of patients and family.

h The original question in Clayton et al. is: "What are the different options available for controlling my pain?" See 2b and 3b: this question was re-formulated to support self-management of patients and family.

- i The original question in Clayton et al. is: "*If I have symptoms, what can be done to improve them? (e.g., pain or discomfort, constipation, shortness of breath, nausea or feeling sick, lack of appetite, tiredness, dry mouth)*". This question was often asked in the context of decreased appetite during consultations of the Center of Expertise Palliative Care. See 2b and 3b: these questions were formulated as one question to support self-management of patients and family.
- j The original question in Clayton et al. is: "*If I have symptoms, what can be done to improve them? (e.g., pain or discomfort, constipation, shortness of breath, nausea or feeling sick, lack of appetite, tiredness, dry mouth)*". This question was often asked in the context of fatigue during consultations of the Center of Expertise Palliative Care. See 2b and 3b: these questions were formulated as one question to support self-management of patients and family.
- k This question occurred in an older version of this QPL combining questions 4 and 5.
- l This question was added based on experience from palliative care consultants. Dutch patients often wish to stay independent and autonomous as long as possible, and often express this in questions about their physical fitness.
- m The original questions in Clayton et al. are: "How can I deal with depression if this occurs?" and "Is there someone I can talk to about my fears and concerns?" See 1a: these questions were combined into one question.
- n The original question in Clayton et al. is: "How can I remain close and intimate with my partner (physically and/or emotionally)?" See 2a: this question was formulated more directly.
- o The original question in Clayton et al. is: "Please tell me the side effects of any new medication you prescribe. How likely are they to occur?". Because patients often ask these questions, this question was split into two questions.
- p The questions about morphine are all based on the questions in the section "Morphine" in the original QPL by Clayton et al. In their QPL, the question "Is it OK for me to drive?" was placed in the section Lifestyle & Quality of Life, but this question was added in this QPL as a question about morphine-like medication. In addition, nausea as a side effect of morphine was added as a question.
- q The original question in Clayton et al. is: "Can you give me advice about treatment decisions that I am discussing with other doctors? For example, whether to stop or start chemotherapy or other treatments". See 3a: this question was re-formulated, as the palliative care consultants do not make treatment decisions, but can explain the future scenarios related to treatment.
- r The original question in Clayton et al. is: "Can someone help me to communicate with other members of my family about what is happening to me?" See 2b and 3b: these questions were formulated as one question to support self-management of patients and family.
- s The original question in Clayton et al. is: "What support is available for other people in the family, such as my carer or my children?" The aspect about children was formulated into a new question.
- t Questions on how to manage care at home (home care and household care) were added to empower the atient and family to self-manage their care.
- u In the Netherlands, the general practitioner or medical specialist remains the coordinator of care; the palliative care consultant is not a co-practitioner (see 3a). Therefore, no specific questions about who to contact in which situation were provided, only the open question.
- v This question replaced the original question in Clayton et al.: "Is there a program of activities available through the palliative care service? (e.g., physiotherapy, massage, spa, breathlessness clinic, day centre)", because palliative care is a consultation-based service and may give advice about certain activities (see 3a).
- w Because palliative sedation and especially euthanasia are part of end-of-life care in the Netherlands, this question was added.
- x The original question in Clayton et al. is: "What costs will I have during my illness (e.g. for any equipment required or medications)?" See 3c: palliative and terminal care are covered by Dutch insurance companies; only questions about the costs of hospice care arose during consultation.
- y In the original question prompt list by Clayton et al., the category "End of life issues" comprises several questions about the end of life. This question attempted to summarize these questions into one.
- z These questions were added to the question prompt list, because these were questions that were often asked during consultations with palliative care consultants of our Center of Expertise Palliative Care.

CHAPTER 7

Non-specialist palliative care - question prompt list preparation: patient, family and clinician experiences

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ABSTRACT

Objectives

Question prompt lists (QPLs) support patients and family to ask questions they consider important during conversations with clinicians. We aimed to evaluate how a QPL developed for specialist palliative care is used during consultations and is perceived by patients and family, and how non-specialist clinicians would use the QPL. We further developed the QPL using these perspectives.

Methods

The QPL is part of a conversation guide on palliative care. Patients and family were asked to select topics and questions before consultation with a palliative care consultant. This qualitative study (2016–2018) included 18 interviews with patients and family who had used the QPL, 17 interviews with non-specialist clinicians and 32 audiotaped consultations with palliative care consultants. The data were analysed thematically and iteratively to adjust the QPL accordingly.

Results

All participants considered the QPL elaborate but recommended keeping all content. Patients and family found that it helps to structure thoughts, ask questions, and regain a sense of control. They also felt the QPL could support them in gathering information. Although it could evoke strong emotions, their real challenge was being in the palliative phase. Clinicians considered the QPL especially helpful as an overview of possible discussion topics. During audiotaped consultations, topics other than those selected were also addressed.

Conclusion

By using the QPL, patients and family felt empowered to express their information needs. Its use may not be as unsettling as clinicians assume. Nevertheless, clinicians who hand out the QPL should introduce the QPL properly to optimise its use.

KEY MESSAGES

What was already known?

- It is important that patients and family are able to express their care needs and questions in order to tailor and offer appropriate palliative care.
- The use of the question prompt list (QPL) developed by Clayton et al. enabled patients and family to ask more questions about prognosis and end of life during palliative care consultations.

What are the new findings?

- Patients and family as well as clinicians found the QPL comprehensive and not too extensive; because of its relevance they would not shorten the QPL.
- Clinicians considered the QPL both as a reminder for themselves to have an overview of what topics can be discussed, and as a helpful tool for patients and family to prepare their consultation; patients and family also used the QPL to discuss topics among themselves.

What is their significance?

- The use of the QPL enabled patients and family to regain a sense of control over their life and future, which helps to make informed and personalised decisions about the end of life.
- Prerequisites for optimal use are that patients and family are already familiar with the concept of palliative care, that patients identify themselves as being in the palliative phase, and, that patients and family have enough time, energy, and inner space to use the QPL.

INTRODUCTION

Palliative care aims to address needs and preferences of patients in the last phase of life, and their family.[1] Effective communication is essential in determining their palliative care needs and values.[2–4] Studies have shown that patients and family have information needs regarding palliative care, what their future will look like, prognosis and the dying phase.[5–8] Specifically, they often do not know what to expect from palliative care consultations, which questions they may ask or what palliative care entails.[9,10] Lack of knowledge decreases feelings of self-efficacy and results in perceived loss of control.[11,12] Providing information can stimulate self-management, help patients and family cope with their current situation and prepare for the future.[5] However, clinicians without formal palliative care training (non-specialists) often do not ask patients about palliative care needs sufficiently, especially when it concerns non-physical domains.[13,14]

Question prompt lists (QPLs) are structured lists of sample questions. These lists aim to support patients and family in formulating questions to obtain the information they need, in identifying their concerns, improving their communication with clinicians and, if possible, in fully participating in consultations and decision-making by expressing their wishes.[15,16] Clayton et al developed a QPL for patients with palliative care needs.[4] Patients who had used this QPL asked more questions, especially about prognosis and the future, compared with patients who had not used a QPL, and did not experience more anxiety than those who had not.[6,17,18] Patients and family who had used QPLs in oncology memorised information better, and consultations were more tailored, while they did not take more time.[19]

In this study, we examined how a palliative care QPL is used and valued for hospital-based palliative care consultations from the viewpoint of patients and family and non-specialist clinicians. Using their perspectives, we further developed the QPL iteratively.

METHODS

Leiden Guide on Palliative Care

The QPL under study is part of the Leiden Guide on Palliative Care. This conversation guide was developed in 2013 by our Center of Expertise in Palliative Care to assess symptom burden and to empower patients and family in identifying and formulating their questions and information needs regarding palliative care. The conversation guide includes the Utrecht Symptom Diary (a Dutch adaptation of the Edmonton Symptom Assessment Scale)[20,21] for symptom assessment and a Dutch adaptation of Clayton et al.'s

QPL on palliative care, to identify information needs (Figure 1).[4] Topics and questions were added to fit the Dutch healthcare system (see Supplement 1). The 2013 version of the QPL was used until the next iteration in October 2018. As part of their routine, the palliative care consultants provided the conversation guide to patients and family a few days before the consultation so that they could select topics to discuss. Patients and family were free to use (parts of) the conversation guide or not. Patients who did not have enough time to prepare for the consultation were either in an acute situation, physically too unfit or dying. Consultations in these situations are mostly aimed at managing a palliative care crisis or the dying phase. Therefore, these patients were not provided with the QPL. We estimate, from our clinical records, that patients and family used the QPL prior to the consultations in 22%.

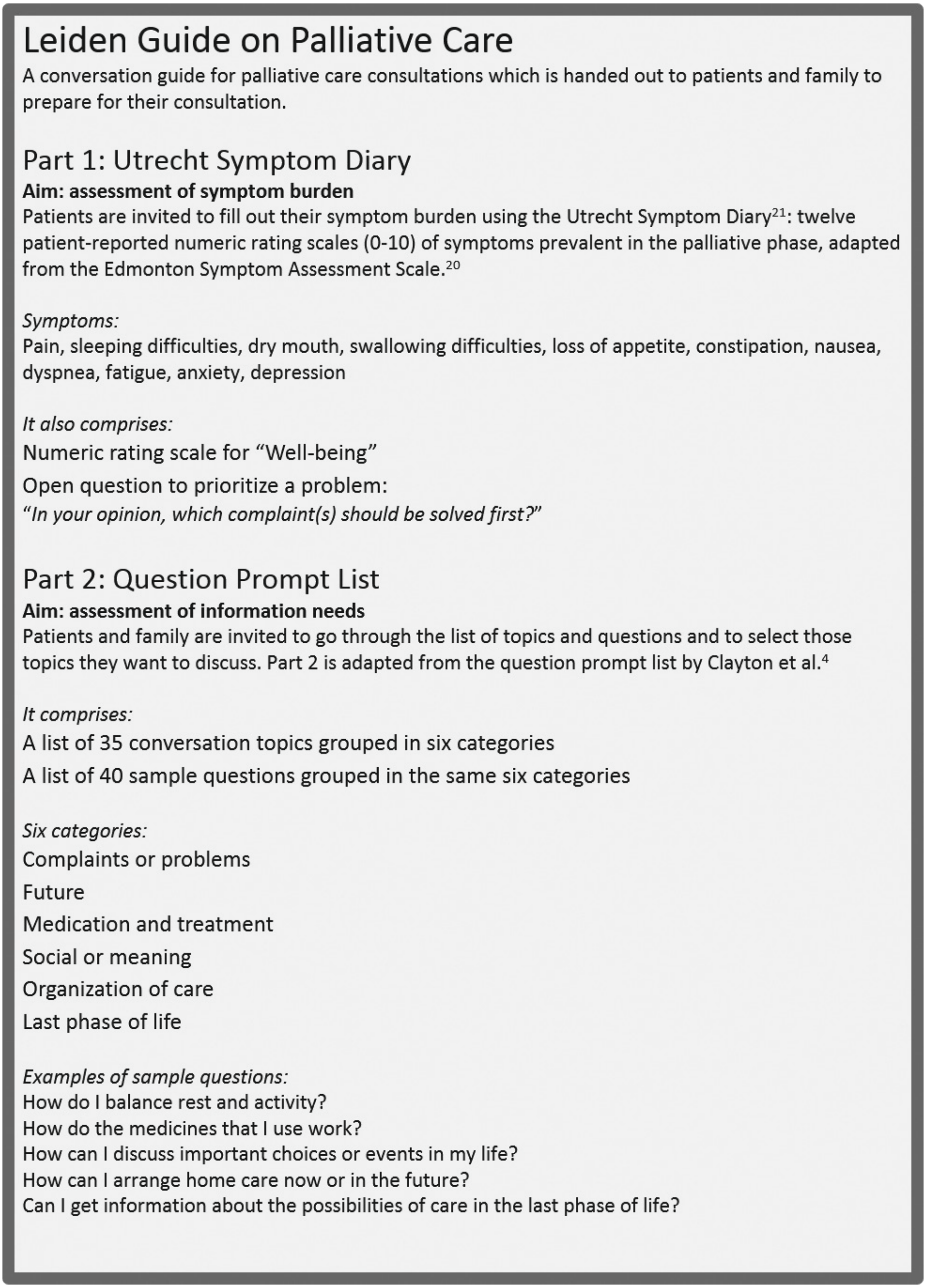
Study design

This study evaluated the use of the QPL-part of the Leiden Guide on Palliative Care with a triangulation of qualitative research methods: thematic analysis of semi-structured interviews and audiotaped consultations. This study took place between August 2016 and December 2018.

Participants and procedures

Consultants of the hospital palliative care team sampled patients and family purposively (regarding diagnosis, age, and gender) to acquire a diverse sample for interviews about their experiences with the QPL (for the topic list, see Supplement 2). It was estimated beforehand that 15 interviews were needed to achieve data saturation. Patients were ineligible if they had not used the QPL, were not clinically fit to be interviewed or if the palliative care consultant estimated their life expectancy <3 months. After obtaining informed consent, a researcher (M-JV, BS, or DW-V) interviewed the patients after the consultation. Family were invited to take part in the interview or to be interviewed instead of the patient if the patient preferred so. Although we aimed at purposive sampling, we found that some patients and family were too exhausted to discuss the full QPL or did not remember in detail how they had used it. In these cases, we had to resort to convenience sampling regarding prognosis or physical functioning; additionally, we further gathered input from the patient and family's perspective through patient and public involvement by interviewing three patient/family advocates from our regional palliative care consortium. These advocates had not used the QPL before and reviewed it before and during the interview.

Clinicians were included for an interview if they had no formal palliative care training,[22] but worked in a medical specialty providing care for patients in the palliative phase on a regular basis. To explore whether these non-specialist palliative care clinicians would support the use of a palliative care QPL and how they would use it, we included clinicians



Leiden Guide on Palliative Care

A conversation guide for palliative care consultations which is handed out to patients and family to prepare for their consultation.

Part 1: Utrecht Symptom Diary

Aim: assessment of symptom burden

Patients are invited to fill out their symptom burden using the Utrecht Symptom Diary[21]: twelve patient-reported numeric rating scales (0-10) of symptoms prevalent in the palliative phase, adapted from the Edmonton Symptom Assessment Scale.[20]

Symptoms:
Pain, sleeping difficulties, dry mouth, swallowing difficulties, loss of appetite, constipation, nausea, dyspnea, fatigue, anxiety, depression

It also comprises:
Numeric rating scale for "Well-being"
Open question to prioritize a problem:
"*In your opinion, which complaint(s) should be solved first?*"

Part 2: Question Prompt List

Aim: assessment of information needs

Patients and family are invited to go through the list of topics and questions and to select those topics they want to discuss. Part 2 is adapted from the question prompt list by Clayton et al.[4]

It comprises:
A list of 35 conversation topics grouped in six categories
A list of 40 sample questions grouped in the same six categories

Six categories:
Complaints or problems
Future
Medication and treatment
Social or meaning
Organization of care
Last phase of life

Examples of sample questions:
How do I balance rest and activity?
How do the medicines that I use work?
How can I discuss important choices or events in my life?
How can I arrange home care now or in the future?
Can I get information about the possibilities of care in the last phase of life?

Fig. 1. Outline of the Leiden Guide on Palliative Care

who had not used the QPL before (Figure 2). Clinicians were purposively sampled via the Center of Expertise in Palliative Care's network until a diverse sample was reached regarding profession, medical specialty, years of working experience and working in or outside the hospital. A researcher (BS) interviewed the clinicians; 15 interviews were planned to achieve data saturation.

Consultants of the hospital palliative care team selected consenting patients and family to audiotape their consultations with a palliative care consultant to explore which topics were addressed. Both patients who had used a QPL and patients who had not used it were included. To evaluate how the QPL was used during consultations, only consultations of patients who had used the QPL were included. To evaluate what topics had been addressed during consultations but are not listed in the QPL, also consultations in which patients had not used the QPL were included.

Further development of the QPL

The QPL was iteratively adapted based on suggestions made by the interviewees, findings from the audiotaped consultations and grey literature (Figure 2). The first revision was done after analysing all consultations, interviews with clinicians and five interviews with patients and family. We aimed to revise the QPL iteratively after each set of five interviews with patients and family, until no additional suggestions emerged from the interviews. Adaptations were made in consecutive research meetings with three palliative care physicians (two general practitioners, and one elderly care physician), two clinical nurse specialists in palliative care, two specialised nurses in palliative care and three researchers.

Data analysis

A trained research assistant transcribed the interviews and consultations verbatim and de-identified all data. Two independent researchers coded the transcripts of the interviews inductively (BS and M-JV: interviews with clinicians; DW-V and M-JV: interviews with patients and family), adhering to Braun and Clarke's method for thematic analysis.[21] Interviews were analysed thematically to explore user experience and usefulness of the QPL during the consultations, and to assess whether topics were missing in the QPL and what should be changed about the QPL. Themes were finalised in consensus meetings and were categorized using a code tree.

For content analysis of the audiotaped consultations (BS and M-JV), a coding scheme was developed (AHP and BS) to code: (1) which topics from the QPL were addressed during consultations; and (2) the person who initiated the discussion of a topic (patient, family, or clinician). A category was considered to have been selected, addressed, or initiated if one of the underlying topics had (Figure 1, Supplement 1). Frequencies are reported using descriptive statistics.

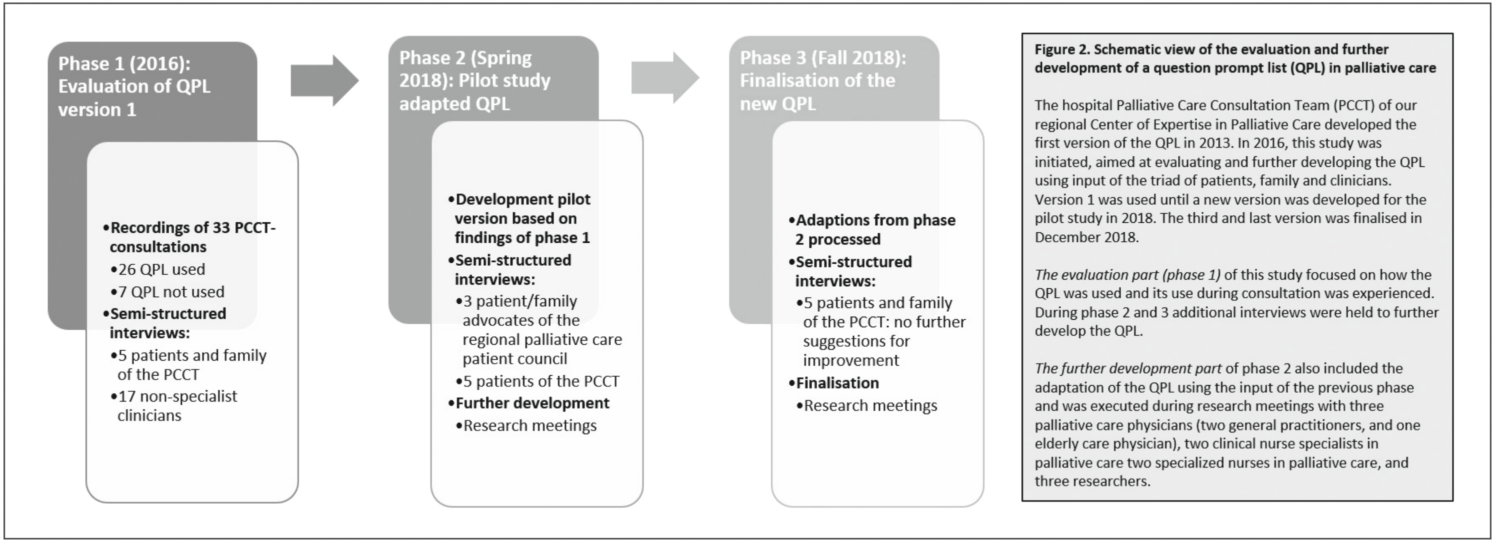


Figure 2. Schematic view of the evaluation and further development of a question prompt list (QPL) in palliative care

The hospital Palliative Care Consultation Team (PCCT) of our regional Center of Expertise in Palliative Care developed the first version of the QPL in 2013. In 2016, this study was initiated, aimed at evaluating and further developing the QPL using input of the triad of patients, family and clinicians. Version 1 was used until a new version was developed for the pilot study in 2018. The third and last version was finalised in December 2018.

The evaluation part (phase 1) of this study focused on how the QPL was used and its use during consultation was experienced. During phase 2 and 3 additional interviews were held to further develop the QPL.

The further development part of phase 2 also included the adaptation of the QPL using the input of the previous phase and was executed during research meetings with three palliative care physicians (two general practitioners, and one elderly care physician), two clinical nurse specialists in palliative care two specialized nurses in palliative care, and three researchers.

Fig. 2. Schematic view of the evaluation and further development of a question prompt list (QPL) in palliative care

RESULTS

Thematic saturation on the use of the QPL and suggestions for improvement of the QPL was reached after 18 interviews with patients and family (including the three patient/family advocates), and 17 interviews with clinicians (Table 1). Of the 33 audiotaped consultations, one recording was excluded from analysis because of poor quality (Table 2; for patient characteristics, see Supplement 3). Three iterations of the QPL were made based on the data; after the third round of interviews with patients and family, no new suggestions to improve the QPL emerged (Supplement 4 and 5).

Use of the QPL among patients and family

Patients and family described the QPL as helpful: its content raised awareness about what palliative care and a palliative trajectory entail. It structured their thoughts about their situation, problems, and questions.

> "It is a very good summary of what might be coming your way. (…) It provides an overview." (patient 13)

They appreciated that the QPL presented topics that they had not thought about before, supported their thinking about what questions they may have, and that it invited them to talk about it.

> "About hospice care, for example, I have never talked about that before, or even thought about it." (patient 1)

> "I found it illuminating to have a list of topics that can be discussed. And presenting the different topics also makes you think about the questions you may have." (daughter of patient 4)

> "I think that this could clearly contribute to an improved relationship between patient and clinician. (…) Because the patient and next of kin often experience a threshold towards a clinician. Um, like: can and am I allowed to ask this." (patient 12)

It could also inspire patients and family to think about topics specific to their situation, even if they were not mentioned in the QPL. The QPL could further evoke discussions between patients and family members:

> “(…) that on the basis of this, by reading about the subjects, you actually start thinking about them, you start talking about them more, like ‘what do you think?’” (daughter of patient 4)

Two participants said that the QPL helped patients to think about and to report their end-of-life wishes, and it is important not to leave this to their family.

Patients and family felt that the QPL enhanced a sense of control by informing them, structuring their thoughts and questions, lowering thresholds to discuss matters, and supporting reporting end-of-life wishes. They often had experienced loss of control because they regarded themselves as knowing nothing about palliative care and palliative care consultations.

> “(…) for us, it was actually the very first time we thought about palliative care, and we really had no idea what to make of it.” (patient 4)

Additionally, their minds were often occupied with many questions, their palliative diagnosis, and the elusiveness of their future:

> “I wasn’t lying there for the fun of it. There was a lot of stuff going through my mind.” (patient 8)

Asking their questions helped them to gather concrete solutions for current and future problems:

> “Yes, and with the answers I now have a better idea of what I am in for. (…) you know what to expect, and what you can do, and what you need help with and how that works.” (patient 17)

> “Maybe later, yes, then this can, you have something to hold on to [indicating the QPL].” (patient 14)

Table 1. Characteristics of interviewees and of patients whose consultations were audiotaped

Interviews		
Patients, family, and patient/family advocates: n=18		
Patient age, median (range)	69	(46-83)
Patient sex, male, n (%)	11	(61)
Role of interviewee, n (%)		
Patient	10	(56)
Family	5	(28)
Patient advocate	3	(17)
Patient primary disease diagnosis[a], n (%)		
Oncological	14	(78)
Dementia/frailty	1	(6)
Complex regional pain syndrome	1	(6)
Haematological malignancy	1	(6)
Others present during interview, n (%)		
Partner	1	(6)
Children	2	(11)
Patient	1	(6)
Other	1	(6)
None	13	(72)
Clinicians: n=17		
Age, median (range)	36	(30-59)
Sex, male, n (%)	2	(12)
Occupation, n (%)		
Medical specialist	8	(47)
Nurse	6	(35)
Resident	3	(18)
Medical specialty, n (%)		
Medical oncology	4	(24)
General practice	3	(18)
Radiation oncology	3	(18)
Orthopaedics	1	(6)
Psychiatry	1	(6)
Surgery	1	(6)
Paediatrics	1	(6)
>1 specialty	2	(12)

Table 1. Characteristics of interviewees and of patients whose consultations were audiotaped (continued)

Audiotaped consultations		
Patients who used a QPL: n=25[b]		
Age, median (range)	67	(46-80)
Sex, male, n (%)	15	(60)
Patient primary disease diagnosis, n (%)		
Oncological	24	(96)
Kidney failure	1	(4)
Median survival, months (IQ-range)	6	(3-51)

Median duration of interviews with patients, family and patient/family advocates was 17 minutes (range: 4-39; the shortest interview was stopped because the patient was called for diagnostic imaging). Median duration of interviews with clinicians was 30 minutes (range: 18-57). Median duration of 25 consultations was 53 minutes (range 38-78).

[a] The primary disease diagnosis of one patient was missing

[b] In total, 32 consultations were recorded; 7 patients had not used the QPL. The median duration of 32 consultations was 53 minutes (range 35-78).

Table 2. Topics from the question prompt list that patients (n=25) selected and that were addressed during their consultation with palliative care consultants.

							Initiator of topic			
	Selected in the QPL		**Addressed during the consultation**		**Selected and addressed**		*Patient or family*		*Palliative care consultant*	
Topic	**%**	**n**	**%**	**n**	**%**	**n**	**%**	**n**	**%**	**n**
Category: Complaints or problems	**92**	**23**	**100**	**25**	**100**	**23**	**88**	**22**	**100**	**25**
Pain	64	16	92	23	100	16	30	7	70	16
Constipation	20	5	76	19	100	5	16	3	84	16
Shortness of breath	28	7	44	11	86	7	27	3	73	8
Nausea	24	6	56	14	83	6	50	7	50	7
Less appetite	40	10	76	19	90	10	37	7	63	12
Fatigue	48	12	88	22	83	12	36	8	64	14
Dry mouth	24	6	60	15	100	6	13	2	87	13
Nutrition	20	5	76	19	100	5	63	12	37	7
Anxiety	28	7	68	17	86	7	35	6	65	11
Depression	28	7	56	14	100	7	29	4	71	10
Sexuality and intimacy	0	0	0	0	N/A	N/A	N/A	N/A	N/A	N/A
Category: Future	**64**	**16**	**68**	**17**	**81**	**16**	**29**	**5**	**77**	**13**
Complaints expected for the future	56	14	60	15	79	14	33	5	67	10
Possibilities for managing future complaints	52	13	32	8	39	13	13	1	88	7
Category: Medication and treatment	**76**	**19**	**96**	**24**	**95**	**19**	**63**	**15**	**96**	**23**

Table 2. Topics from the question prompt list that patients (n=25) selected and that were addressed during their consultation with palliative care consultants. (continued)

	Selected in the QPL		**Addressed during the consultation**		**Selected and addressed**		**Initiator of topic**			
							Patient or family		*Palliative care consultant*	
Topic	**%**	**n**	**%**	**n**	**%**	**n**	**%**	**n**	**%**	**n**
Side effects of medication	24	6	56	14	100	6	43	6	57	8
Medication intake times	20	5	48	12	100	5	17	2	83	10
Next steps medication	32	8	60	15	75	8	13	2	87	13
Medication for worsening complaints	44	11	48	12	64	11	8	1	92	11
Types of morphine-like medication	32	8	60	15	100	8	33	5	67	10
Choice of whether or not to treat the disease	44	11	48	12	64	11	50	6	50	6
Choice between treatment and quality of life	64	16	52	13	75	16	39	5	62	8
Category: Social or meaning	**40**	**10**	**68**	**17**	**100**	**10**	**53**	**9**	**53**	**9**
Help or information for children	28	7	44	11	100	7	27	3	73	8
Help or information for relatives	32	8	32	8	88	8	25	2	75	6
Meaning of life	4	1	20	5	0	1	80	4	20	1
Category: Organization of care	**68**	**17**	**100**	**25**	**100**	**17**	**68**	**17**	**96**	**24**
Home care	44	11	80	20	91	11	30	6	70	14
Household care	8	2	20	5	100	2	0	0	100	5
Hospice care	44	11	52	13	91	11	46	6	54	7
Volunteers	8	2	20	5	100	2	40	2	60	3
Point of contact for complaints	44	11	60	15	82	11	33	5	67	10
Role of the general practitioner	40	10	100	25	100	10	24	6	76	19
Possibilities of care	44	11	36	9	36	11	22	2	78	7
Category: Last phase of life	**56**	**14**	**88**	**22**	**99**	**14**	**91**	**20**	**77**	**17**
Palliative sedation	24	6	48	12	67	6	8	1	92	11
Euthanasia	40	10	68	17	100	10	47	8	53	9
Fluids and nutrition	16	4	24	6	50	4	50	3	50	3
Practical matters of the end of life	24	6	40	10	67	6	90	9	10	1
Course of the last phase of life	36	9	48	12	44	9	75	9	25	3

Patients and family were asked to select the topics they wanted to discuss during their consultation with a palliative care consultant. Their selections of topics were compared with the topics that were addressed during their actual consultation and who initiated the topic during the consultation.
The totals of topics may exceed the total of addressed categories, since a category was considered selected, addressed, or initiated if one of the underlying topics was.

Patients and family considered the possibility to indicate which topic or question to discuss, before, during and after the consultation, convenient.

> "I also indicated that by ticking the boxes. I like that." (patient 5)

They said that the QPL supported asking specific questions during the consultation. During consultations, the QPL was used to gather practical information about specific topics and to make notes. After the consultation, patients sometimes used the QPL as a reminder to discuss some topics later, or re-used it in consultations with other clinicians involved, such as the general practitioner or medical oncologist.

Usefulness of the QPL among non-specialist clinicians

Clinicians hypothesised that the QPL could be useful for them as an overview of information needs patients and family may have, and as a manual with topics relevant to palliative care conversations. They thought that it would help them focus more on patients' and families' needs.

> "It [the QPL] requires more depth, but I think that is something the clinician has to look for. (...) I really see this as a helpful tool to support the conversation." (clinician 14)

They thought that the QPL could be used to check whether all relevant topics had been covered.

> "I think it is a fantastic reminder, but actually even more for the physician than for the patient." (clinician 5)

Especially topics regarding the future were considered important:

> "I think especially the future, indeed [is a topic that often emerges in conversations about palliative care]. (...) I think that that is something patients primarily want clarity about." (clinician 3)

Some clinicians indicated that the QPL could be supportive as it listed topics they used to explain 'future scenarios' to patients and family:

> "We always try to list every possible scenario. Apart from the symptoms. (...) And then we try to go through them, and we try to make a plan." (clinician 15)

Barriers to QPL use

Patients, family, and clinicians identified several barriers to using the QPL (Table 3). Some patients and family indicated that they had not been properly informed yet about their disease phase or the concept of palliative care, or that they had not thought about it; this made them unprepared for some topics presented in the QPL. Other reported barriers were not being able to use the QPL because of lack of space, time, and energy to go through the QPL and not having a trusting relationship with their clinician to discuss delicate topics. Three patients were unable to emotionally relate to the palliative care topics; they found them too challenging and skipped the sections they thought did not apply to them. Nonetheless, they understood these topics would become important at some point or may already be relevant to others and they felt it was right that the topics were part of the QPL. Optimal use of the QPL was further thought to be impeded

Table 3. Barriers to use, value of the question prompt list, and recommendations for clinicians

Barriers to use and value	Recommendation for clinicians
Patient-related barriers	
Patient cannot identify himself as being palliative	Introduce concept of palliative care to patient and family
	Explain what the QPL is: it is a tool providing insight into symptom burden and information needs that can be discussed during a consultation about palliative care
	Explain how the QPL can be used: irrelevant or unsettling parts can be skipped
Patient is not able to use the QPL • Not enough space, time, and energy to think over and fill out • Decreased cognitive ability, unable to comprehend	Family can fill out the QPL if the patient is not able to use it
	Hand out the QPL at least several days before the consultation takes place
Clinician-related barriers	
Not sure if the QPL can be handed out to every patient in the palliative phase	The QPL can be used for all patients in the palliative phase and their family
Going through the QPL may take too much time	More than one consultation can be scheduled to discuss the QPL
	Ask the patient at the beginning of the consultation what he or she considers the most important topic to discuss
Not sure which clinician should discuss the QPL	Refer to another clinician or healthcare professional when topics are outside the field of expertise of the clinician or in case time is lacking: nurse specialist, psychologist, social worker, spiritual counsellor

List of abbreviations: QPL, question prompt list when patients and family had just received bad news, or when they were busy arranging medical visits and care. Some patients and family indicated that patients with cognitive problems would be unable to understand the QPL.

Most clinicians regarded the QPL as too extensive for discussion in a single consultation of 10–15 min. They indicated they would only discuss the topics within their expertise and refer to other clinicians for the remaining, plan a second consultation or delegate the consultation to a (specialised) nurse.

Topics selected and addressed during consultations

The QPL was used in 25 audiotaped consultations (Table 2). A median of 18 topics were addressed during consultations (range: 11–28). Overall, more topics were addressed than patients had selected. Thirteen topics and the categories *Complaints or problems*, *Social or meaning* and *Organisation of care* were always addressed if these were selected. *Sexuality and intimacy* was never selected, nor discussed during the consultations. *Role of the general practitioner* was addressed during all consultations, despite it not often having been selected. Overall, palliative care consultants initiated topics more often than patients and families did, except for topics about the *Last phase of life*. Patients and family most often initiated the topics *Meaning of life*, *Practical matters of the end of life* and *Course of the last phase of life*. The palliative care consultant most often initiated the topics *Household care*, *Medication for when I suddenly get more complaints* and *Palliative sedation*.

Suggestions to improve the content of the QPL

Overall, the QPL's content was considered to be comprehensive and relevant. Table 4 displays suggestions for additional topics and questions that patients, family and clinicians mentioned. They all wanted to add content but had different ideas about which content should be added. The interviewees noted that all topics in the QPL can be relevant to patients in the palliative phase and their family:

> "Oh, you don't want to know everything we're thinking about now. That is basically everything that is also in there [indicating the conversation guide]." (patient 11)
> "Everything [in the QPL] is relevant. It is a very good list. Not too much, not too little." (clinician 12)

Patients and family recommended keeping all topics and questions: topics irrelevant to themselves might be relevant to others; and clinicians agreed. Patients, family, and clinicians commented that they would not initiate discussing *Sex and intimacy* during a consultation:

"Well, I would be hesitant to discuss sexuality and intimacy, for example, with these ladies." (patient 1); however, no-one wanted to exclude the topic. We changed *Sexuality and intimacy* into *Intimacy and sexuality* to make the topic easier to discuss.

Table 4. Input for improvement of question prompt list by patients, family and clinicians, transcribed consultations and Arthur et al.'s[22] consensus list of prompt questions

Content added to question prompt list[a]	
Source	*Subject*
18 interviews with patients and family	• Wishes for the last phase of life • Religion and view on life • Spiritual and psychological help • Treatment possibilities • Contact details for acute situations • Self-care for informal caregivers
17 interviews with clinicians	• Relationships and family • (limitations on) hospitalizations • Contact persons in specific situations • Future scenarios
33 transcribed consultations	• Independence • Psychological care
Comparison with consensus list of prompt questions[22,b]	• Questions about informal caregivers • Questions for informal caregivers
Adjusted lay-out and wording of the question prompt list	
Source	*Subject*
Interviews, consultations, and grey literature	• Shape of the document was changed from 5 A4 sheets to a 11-page printable booklet (A5) • Lay-out and order of topics and questions were revised • Wording was checked and improved according to Dutch level B1 according to the European Council: "*Can understand the main points of clear standard input on familiar matters regularly encountered in work, school, leisure*"[23] • Cover page with instructions for patients and family was made more clear • Supplemental leaflet with advice for use and to overcome barriers for clinicians

[a] Patients, family, patient/family advocates and clinicians preferred no adaptations to the content of the question prompt list.

[b] Arthur et al.[22] published a study in clinicians to list the most important prompt questions, which was used by our research group to compare if content should be added to our question prompt list.

Emotional challenge of using the QPL

Some clinicians indicated topics that might be emotionally challenging and should not be presented too early in the disease trajectory, meaning not to patients with advanced cancer who still undergo curative treatments. Most patients and family did not feel that using the QPL was more emotionally challenging than being confronted with the knowledge of having a potentially incurable disease. They mentioned that discussing the palliative phase was part of the disease trajectory; they therefore considered all items in the QPL to be relevant:

> “These are not nice topics, of course not, (…) but I personally find these kinds of subjects challenging. Like, well yes, the time will come, so you should be as prepared as possible.” (patient 2).

DISCUSSION

Main findings

This study evaluated the use of a QPL as part of a conversation guide on palliative care, by means of interviews with patients, family, patient/family advocates and clinicians without formal palliative care training (non-specialists), and by audiotaping consultations with palliative care consultants. Patients and family indicated that the QPL had supported them in thinking about their care preferences and sharing their needs during consultations. Some content could evoke strong emotions in them, but their real challenge was being in the palliative phase. The clinicians indicated that the QPL could help remind them to address relevant palliative care issues. The QPL was improved according to the perspectives of patients, family, and clinicians (Supplements 6 and 7). Barriers to optimal use reported by interviewees included insufficient introduction of patients and family to palliative care and the QPL, lack of time and energy to go through the QPL and patients not seeing themselves as being in need of palliative care.

All interviewees considered the content of the QPL to be relevant, clear, and comprehensive, and useful to prepare for palliative care consultations. Arthur et al. shortened the original QPL on which the present one was based using a Delphi study among clinicians, because of evidence suggesting that clinicians would prefer a brief QPL.[4,23] The patients, family, and clinicians in our study, similar to Clayton’s study,[4] considered the QPL to be extensive, but they would not shorten it, preferring a broader scope of topics. One topic, *Sexuality and intimacy*, was never selected or discussed. Interviewees doubted they would initiate this topic. Cathcart-Rake et al. reported clinicians would not discuss sexuality and intimacy in palliative care because they prioritise a holistic view, have time constraints, are not used to talking about sexuality and intimacy or experience it as a taboo.[24] At the same time, many palliative care patients have unmet intimacy needs: 48% reported their illness impacted their intimacy; and >75% thought discussing intimacy was helpful both for patients who died within 3 months and patients who lived longer than 3 months.[25] We therefore recommend clinicians to bring up this topic during palliative care consultations and so invite patients and family to indicate whether they need information about intimacy and sexuality.

Patients and family reported that the QPL's content helped them to think about, formulate and discuss their questions and wishes and helped them gain an overview of what the future could hold for them, which corresponds with existing literature.[4,17,26] In general, information helps patients to regain a sense of control over self-management.[5] Patients felt further supported by the QPL because it educated them about palliative care and their possible needs in this regard. Our patients and family described loss of control when referred to the palliative care consultant, comparable with Rolland's 'crisis phase'.[27] During this crisis phase, patients and family need to adapt to the situation with the new (incurable or palliative) diagnosis and only then, they can move on to adapting a more practical understanding about the illness and the new healthcare setting.

Non-specialist clinicians considered the QPL helpful for patients and family to ask specific questions, corresponding with previous studies.[4,28] Rogg et al. found that clinicians find discussing prognosis and future difficult for several reasons and might avoid these discussions.[29] In our study, the clinicians mentioned that the QPL provided them with an overview of future scenarios to discuss with patients and family. Literature shows that the future is often an information need in patients and family.[6,30] However, our findings from the analysis of the actual consultations demonstrate that patients more often selected items about *Complaints or problems* and *Organisation of care*.

Discussions are facilitated when patients, family and clinicians explicitly agree on and allow each other to discuss difficult topics.[31] In our study, patients and family felt that the QPL gave them permission to ask questions. By empowering patients and family, the QPL aids clinicians to formulate recommendations that are tailored to end-of-life preferences. This corresponds with Galekop et al.'s results on patient–clinician collaboration: palliative care specialists and volunteers viewed patient-centred care as the patient being either in the driver's seat (i.e., respecting the patient's autonomy at all times), or in the passenger seat (i.e., collaborating with the patient and other clinicians and stepping in when the patient cannot decide for themselves; when he is too tired or insufficiently informed).[32] Remarkably, items about the last phase of life were the only items that were initiated more frequently by patients and family than by the consultant. Perhaps patients and family perceive a consultation on palliative care as an opportunity to talk about the end of life, or consultants considered these to be delicate topics and adopted more of a 'wait-and-see' attitude.

Patients, family, and patient/family advocates indicated that a proper introduction to palliative care and the QPL is key: both should be explained to patients and family before handing out the QPL. Additionally, they must have enough inner space, time, and energy to use it (Table 3). Effective communication about palliative care has been shown to depend on the context, disease stage, a good patient–clinician relationship, mutual understanding between patients and clinicians and ‘readiness’ of patients and family.[31,33] This was confirmed by our findings: in order for the QPL to be effective, several barriers have to be overcome in clinical practice. Clinicians participating in our study provided suggestions for dealing with these barriers, which we used to develop an instruction leaflet for clinicians. In our study, a minority of patients were not yet able to identify themselves as palliative care patients, but they found the QPL no more unsettling than their current situation, which is in line with other findings.[16] Fliedner et al. demonstrated that although patients with advanced cancer found early palliative care consultations emotionally challenging, a QPL allowed them to plan for the future without considering use of the QPL itself burdensome.[34] Gatekeeping by clinicians may even disempower patients and family in expressing their needs. Therefore, clinicians should not hesitate to offer patients and family a QPL to prepare their consultation; patients and family can decide for themselves whether or not to use it. To date the QPL has only been used in the setting of specialised palliative care, but the diverse group of non-specialist clinicians who participated in our study indicated that the QPL could also be used by non-specialist clinicians. They indicated that they would refer to the appropriate palliative care clinician if patients and loved ones have complex questions or problems. This corresponds with the palliative care model described by Henderson et al.: most palliative care is provided by non-specialist clinicians, and palliative care specialists have the responsibility to educate and support their non-specialist colleagues.[35] This model of palliative care allows a more integrated approach with current care and early discussion of the wishes, needs and values of patients and their family. To make the QPL more suitable for use by patients of non-specialist clinicians, we used their input to adapt the QPL accordingly.

Strengths and weaknesses

This qualitative study evaluating the use of a palliative care QPL included a triangulation of 35 semi-structured interviews with patients, family, and clinicians and 32 audiotaped consultations. Including only patients who used the QPL for individual interviews may have resulted in an overly optimistic view of the QPL. We had decided to include patients with a life expectancy of at least 3 months; earlier experiences with including patients for who had a shorter life expectancy, showed them to be often too tired to participate in a qualitative interview, which makes including them unethical. This may have led to an over-representation of perspectives of patients and family in relatively good health, and to the inclusion of relatively more patients with a diagnosis of cancer compared with other life-limiting diagnoses. However, by asking patient advocates who had a loved one who had died and who had not used the QPL before, we believe we overcame these gaps introduced by selection bias through interviewing those who used the QPL and through a life expectancy of at least 3 months.

Further research

Our study included mostly patients with cancer, similar to most studies on QPLs in palliative care.[15,36] Before implementing the QPL for use by non-specialist palliative care clinicians, qualitative research is needed on how they experience use of the QPL in clinical practice: the effect of using the QPL, facilitators and barriers to using the QPL effectively and how much training is required for them to use the QPL appropriately. Next, a study with cluster-randomised design in non-specialist clinicians can indicate its effect on patient outcomes. We also recommend further research on whether the interviewees' suggestions are sufficient in improving person-centred communication and patient empowerment. We studied the use of a QPL as a strategy to improve consultations with individual patients and family. Wider and systemic implementation should be preceded by clinical trials evaluating its effect in other patient populations and healthcare settings, such as in general practice and nursing homes. Future research aims include examining the effect of combining a symptom assessment scale and a QPL on perceived quality of care, and the effect of QPLs on patient autonomy and quality of life.

CONCLUSION

Patients and family considered the QPL to be relevant, clear, and comprehensive. The QPL was thought to support patients and family in structuring their thoughts and in formulating and asking their questions. They felt better prepared for their current situation and the future. Clinicians can use the QPL as an overview of topics relevant in palliative care and to tailor consultations to the needs of patients and family. Although the QPL could evoke negative emotions, patients and family understood the necessity and usefulness of discussing these topics. Reported barriers to optimal use were insufficient introduction of patients and family to palliative care and to the QPL, patient lack of time and energy to use it, and patients not relating the topics integral to palliative care to themselves.

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Contributors

AHP, EDN and YvdL provided the conceptual framework for this study. M-JV, EDN, BS and DW-V contributed to data collection. M-JV, BS and DW-V analysed the data. NH was involved in analysis of quantitative data. M-JV wrote the manuscript and all authors contributed by providing critical comments on the manuscript. M-JV is the guarantor of the content.

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Competing interests

None declared.

Patient consent for publication

Not applicable.

Ethics approval

The Medical Ethical Committee of Leiden University Medical Center approved this study (on 14 July 2016, reference number P16.112). Participants gave informed consent to participate in the study before taking part.

Provenance and peer review

Not commissioned; externally peer reviewed.

Data availability statement

Data are available upon reasonable request. All data relevant to the study are included in the article or uploaded as supplementary information. All relevant data is shown in the manuscript; the authors may provide additional data upon reasonable request.

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SUPPLEMENTARY MATERIALS

Supplement 1

Table. Classification of categories, topics, and questions of the question prompt list of the Leiden Guide on Palliative Care.

Topic prompt list	Question prompt list	
Category: Complaints or problems		
N/A	1	If I have symptoms, what can be done to improve them?[a]
	2	What can I do myself to reduce my symptoms?[b]
	2b	What are the different options available for controlling my symptoms?[c]
	3	How do I achieve the highest possible quality of life with my symptoms?[d]
	7	How can I still do the things that are important to me?[e]
	13	Where can I find reliable information, websites or flyers?[f]
Pain	10	How can I reduce pain?[g]
	10a	Can you help me reduce my pain?[g]
	10b	What else can I do myself to reduce the pain?[h]
Constipation	*N/A*	-
Shortness of breath	*N/A*	-
Nausea	*N/A*	-
Less appetite	8	What kind of food should I eat?
	9	What can I do to get more appetite for food?[i]
Fatigue	4	I am very tired, how do I deal with this?[j]
	5	How much activity or exercise is too much and how much is too little?
	4_5	I am very tired; how do I deal with rest and activities?[k]
	6	What can I do to stay in shape?[l]
Anxiety	12	Who can help me with depression and anxiety?[m]
	12	Who can help me with depression and anxiety?[m]
Dry mouth	*N/A*	-
Nutrition	*N/A*	-
Sexuality and intimacy	11	I don't feel like having sex or cuddling, how do I deal with this?[n]
Future		
Complaints expected for the future	14	What symptoms may occur in the future and what should I do if they arise?
	15	Will I be in pain?
Possibilities for managing complaints in the future	16	Will my pain and other symptoms be controlled in the future?

Table. Classification of categories, topics, and questions of the question prompt list of the Leiden Guide on Palliative Care. (continued)

Topic prompt list	Question prompt list	
Medication and treatment		
N/A	27	Are there other painkillers or alternatives available?
	28	What are all my tablets for?
Side effects of medication	29	What side effects do the medicines I use have?[o]
	30	What is the chance that I will get side effects?[o]
	31	What can be done about side effects?
Medication intake times	32	How and when should I take my medication?
Next steps medication	*N/A*	-
Medication for when I suddenly get more complaints	*N/A*	-
Types of morphine-like medication	33	If I use morphine (or a morphine-like medicine), can I:[p] − become addicted, so it no longer works, or I need more and more? − stop taking it if my pain goes away? − get sleepy or confused? − drive? − get nauseous or constipated (difficulty or unable to defecate)?*
Choice of whether or not to treat the disease	35	What can be done if I choose not to treat the disease anymore (for example if I stop taking chemotherapy)?[q]
Choice between treatment and quality of life	34	What does the treatment of the disease do to my quality of life?[z]
Social or meaning		
N/A	20	How can I discuss important choices / events in my life?[r]
	21	How do I find a way of saying goodbye that suits me?[z]
Help or information for my children	17	Where can I find good help / guidance for my children?[s]
	18	Are there good websites for (young) children?[z]
Help or information for the people around me	19	Which websites / organizations can help my family and friends (caregivers)?[s]
Meaning or philosophy of life	22	My view of the meaning of life and about life after death is changing. How do I deal with this?[z]

Organization of care		
Home care	23	How can I arrange home care or household care now or in the future?[t]
	23a	How can I arrange home care now or in the future?[t]
Household care	23	How can I arrange home care or household care now or in the future?[t]
	23b	How can I arrange household care now or in the future?[t]
Hospice care	*N/A*	-
Volunteers	24	Are there any volunteers available to help me? (e.g. to take me to an appointment or to do the shopping)
Point of contact for symptoms	25	Who do I call in case of symptoms?[u]
Role of the general practitioner	*N/A*	-
Possibilities of care	26	Can I get help with an activity, travel or trip?[v]
Last phase of life		
Palliative sedation	37	Can I get information about palliative sedation or euthanasia?[w]
Euthanasia	37	Can I get information about palliative sedation or euthanasia?[w]
Fluids and nutrition	38	How do I deal with fluid and nutrition in the event of illness or the end of life?[z]
Practical matters of the end of life	39	Can I get information about the possibilities of care in the last phase of life?
	40	What are the costs of care (for example home care / hospice)?[x]
Course of the last phase of life	36	Can I get information about the last weeks of life?*[y]

List of abbreviations: N/A: not applicable.
Legends: Because the topic prompt list and question prompt list were separately presented in the Leiden Guide on Palliative Care, the above depicted classification was made to report how often categories and topics were indicated. Some questions did not belong to one specific topic. Topics could be grouped with more than one question and to zero questions. a-z: adaptations made to the question prompt list (see below)

Construction of the question prompt list
The Center of Expertise Palliative Care of Leiden University Medical Center constructed a Dutch version of Clayton et al.'s question prompt list (QPL) on palliative care in 2013. In team meetings with the palliative care consultants, it was concluded that the QPL needed practical, cultural and organizational adaptations. The QPL consisted of 35 topics and 40 questions in 6 categories. The QPL became part of a conversation guide, the Leiden Guide on Palliative Care, which also included the Utrecht Symptom Diary for assessing symptom burden on symptom assessment scales.

1. Practical:

a. Palliative care consultants estimated that many of their patients would lack energy and time to view all questions in Clayton et al.'s QPL. Therefore, they selected the most important questions and formulated a topic prompt list consisting of all relevant topics, which preceded the list with questions. Questions on "Spiritual and Cultural support" were left out.
b. Questions about symptoms were specified for each symptom, because these would support the symptom assessment scales that the palliative care consultants also used as part of their consultations.
c. Patients often asked questions about the truths and falsehoods about morphine and morphine-like medication, thus questions about this topic were made more specific.

d. Questions for family were excluded in this first version, because palliative care consultants focused primarily on the patient.
e. The palliative care consultation team already used a folder containing information sources (flyers, leaflets and websites), which they could hand out to patients and family during consultations.
f. Contact details of the palliative care consultation team were not a part of the QPL because they had their own business card to hand out.

2. Cultural:
a. Some questions were formulated more directly, which many Dutch people are used to.
b. Personal autonomy is a highly respected principle in the Netherlands; some questions were therefore formulated in such way that patients can maintain self-control.

3. Organizational:
a. In the Netherlands, palliative care consultants are often consulted to get their advice, and do not have the role of co-practitioners. They therefore do not actively participate in decisions about the treatment of the patient's disease.
b. The aim of a palliative care consultation is to empower patients and family and to improve self-management. The formulation of some questions in Clayton et al.'s QPL was changed into a more active form, so that the patient can ask what he or she can do or organize care.
c. Palliative care is covered by Dutch insurance companies, so questions about financial support were omitted.

Adaptations made to the question prompt list
a The original question in Clayton et al. is: "*If I have symptoms, what can be done to improve them? (e.g. pain or discomfort, constipation, shortness of breath, nausea or feeling sick, lack of appetite, tiredness, dry mouth)*". The Center of Expertise Palliative Care experienced that patients would rather have the question divided into one question for each symptom.
b The original questions in Clayton et al. are: "Can you help to control my pain?" and "Can you help to control my other symptoms?". See 2a: this question was formulated more directly.
c The original questions in Clayton et al. are: "Can you help me to control my other symptoms?" and "What are the different options available for controlling my pain?" See 2a: this question was formulated more directly.
d The original question in Clayton et al. is: "How can I make the most of my life?" See 1b: the relation to symptoms was added to the formulation of the question.
e The original question in Clayton et al. is: "What can I expect to be able to do?"
f The original questions in Clayton et al. are: "What information is available about palliative care and my illness?" and "Are books, videos or pamphlets available?" See 2b and 3b: these questions were formulated as one question to support self-management of patients and family.
g The original question in Clayton et al. is: "Can you help to control my pain?" See 2b and 3b: this question was re-formulated to support self-management of patients and family.
h The original question in Clayton et al. is: "What are the different options available for controlling my pain?" See 2b and 3b: this question was re-formulated to support self-management of patients and family.
i The original question in Clayton et al. is: "*If I have symptoms, what can be done to improve them? (e.g., pain or discomfort, constipation, shortness of breath, nausea or feeling sick, lack of appetite, tiredness, dry mouth)*". This question was often asked in the context of decreased appetite during consultations of the Center of Expertise Palliative Care. See 2b and 3b: these questions were formulated as one question to support self-management of patients and family.
j The original question in Clayton et al. is: "*If I have symptoms, what can be done to improve them? (e.g., pain or discomfort, constipation, shortness of breath, nausea or feeling sick, lack of appetite, tiredness, dry mouth)*". This question was often asked in the context of fatigue during consultations of the Center of Expertise Palliative Care. See 2b and 3b: these questions were formulated as one question to support self-management of patients and family.
k This question occurred in an older version of this QPL combining questions 4 and 5.
l This question was added based on experience from palliative care consultants. Dutch patients often wish to stay independent and autonomous as long as possible, and often express this in questions about their physical fitness.
m The original questions in Clayton et al. are: "How can I deal with depression if this occurs?" and "Is there someone I can talk to about my fears and concerns?" See 1a: these questions were combined into one question.
n The original question in Clayton et al. is: "How can I remain close and intimate with my partner (physically and/or emotionally)?" See 2a: this question was formulated more directly.

o The original question in Clayton et al. is: “Please tell me the side effects of any new medication you prescribe. How likely are they to occur?”. Because patients often ask these questions, this question was split into two questions.

p The questions about morphine are all based on the questions in the section “Morphine” in the original QPL by Clayton et al. In their QPL, the question “Is it OK for me to drive?” was placed in the section Lifestyle & Quality of Life, but this question was added in this QPL as a question about morphine-like medication. In addition, nausea as a side effect of morphine was added as a question.

q The original question in Clayton et al. is: “Can you give me advice about treatment decisions that I am discussing with other doctors? For example, whether to stop or start chemotherapy or other treatments”. See 3a: this question was re-formulated, as the palliative care consultants do not make treatment decisions, but can explain the future scenarios related to treatment.

r The original question in Clayton et al. is: “Can someone help me to communicate with other members of my family about what is happening to me?” See 2b and 3b: these questions were formulated as one question to support self-management of patients and family.

s The original question in Clayton et al. is: “What support is available for other people in the family, such as my carer or my children?” The aspect about children was formulated into a new question.

t Questions on how to manage care at home (home care and household care) were added to empower the patient and family to self-manage their care.

u In the Netherlands, the general practitioner or medical specialist remains the coordinator of care; the palliative care consultant is not a co-practitioner (see 3a). Therefore, no specific questions about who to contact in which situation were provided, only the open question.

v This question replaced the original question in Clayton et al.: “Is there a program of activities available through the palliative care service? (e.g., physiotherapy, massage, spa, breathlessness clinic, day centre)”, because palliative care is a consultation-based service and may give advice about certain activities (see 3a).

w Because palliative sedation and especially euthanasia are part of end-of-life care in the Netherlands, this question was added.

x The original question in Clayton et al. is: “What costs will I have during my illness (e.g. for any equipment required or medications)?” See 3c: palliative and terminal care are covered by Dutch insurance companies; only questions about the costs of hospice care arose during consultation.

y In the original question prompt list by Clayton et al., the category “End of life issues” comprises several questions about the end of life. This question attempted to summarize these questions into one.

z These questions were added to the question prompt list, because these were questions that were often asked during consultations with palliative care consultants of our Center of Expertise Palliative Care.

Supplement 2

Topic list for interviews

Interview guide for the interviews with patient and family and patient/family advocates

About the question prompt list in general

- What do you think about the question prompt list?
- What do you like about the question prompt list?
- What do you dislike about the question prompt list?
- Is the question prompt list clear to you?
- Have you read all the topics and questions?

o What was the reason that you did not read everything?
o Did you read through one time or several times?
o Did you go through the conversation guide on your own or with someone else?

- What did you think of the length of the question prompt list?
- Were there any parts of the question prompt list that you found unclear?

o What did you find unclear?

- When did you go through the question prompt list?

o (Did you go through the question prompt list before and/or after the conversation with the palliative care consultant? How much time before your conversation with your palliative care consultant?)

- Did the question prompt list facilitate talking about a difficult topic?

Overview of possible discussion topics and questions

- Do you feel that all conversation topics are clearly formulated?
- Are there discussion topics in the question prompt list that you find relevant and that you had not thought of yourself to discuss with the palliative care consultant?
- Did you find some topics unsettling to think about?

o If yes, which subjects?
o After ticking these topics, did you talk to your loved ones about these topics?

- Did you find some subjects too personal to discuss during the consultation?
- What did you think of the sample questions?
- Did you yourself have any questions?
- Did you think of new questions thanks to the example questions?
- Did they help you ask more questions during the consultation?
- What did you think of the number of sample questions? (too many / too few)

- What did you think of the overlap between the topics of discussion and the overview of the questions? (this question was added when the overlap was raised several times during interviews)

Consultation

- Did the question prompt list help you get an idea of what would be discussed during the consultation?
- Did the question prompt list help you to ask the right questions in the conversation with the palliative care consultant?

After consultation

- Has the question prompt list helped you better identify the questions you have about your future?

Per topic

- Which subjects do you think can be left out?
- Which topics need to be added?
- Which example questions do you think can be left out?
- Do example questions need to be added?

Interview guide for the interviews with clinicians

Structured part of the interview

- Sex
- Age
- Working in which department
- Working as
- How many years have you been active as a care provider (including training years)?
- How many palliative patients do you see per month?
- How often per month do you have a bad news conversation with a patient?
- How many times a month do you have conversations with patients in which end-of-life issues are addressed?
- Do you find it difficult to start bad news conversations with patients?

Helpfulness of topics

- Do you consider the topics of the category Complaints helpful?
- Do you consider the topics of the category Future helpful? Do you consider the topics of the category Medicine and treatment helpful?
- Do you consider the topics of the category Social and meaning helpful?

- Do you consider the topics of the category Organization of care helpful?
- Do you consider the topics of the category Last phase of life helpful?
- Do you consider the example questions helpful? (going through all questions)
- What do you think of the order of the topics?
- Should any topics be added?
- Should any topics be left out?
- What is your opinion about the question prompt list?
- Do you think the question prompt list comprises unsettling topics?
- Hypothetical use of question prompt list (how would you use the question prompt list?)
- Other remarks

Supplement 3

Table. Characteristics of the n=32 patients whose consultation was audiotaped

Patient characteristics[a]		
Age, median (range)	65	(46-80)
Sex, male, n (%)	17	(53)
Patient primary disease diagnosis, n (%)		
Oncological	31	(97)
Kidney failure	1	(3)
Median survival, months (IQ-range)	6	(3-51)

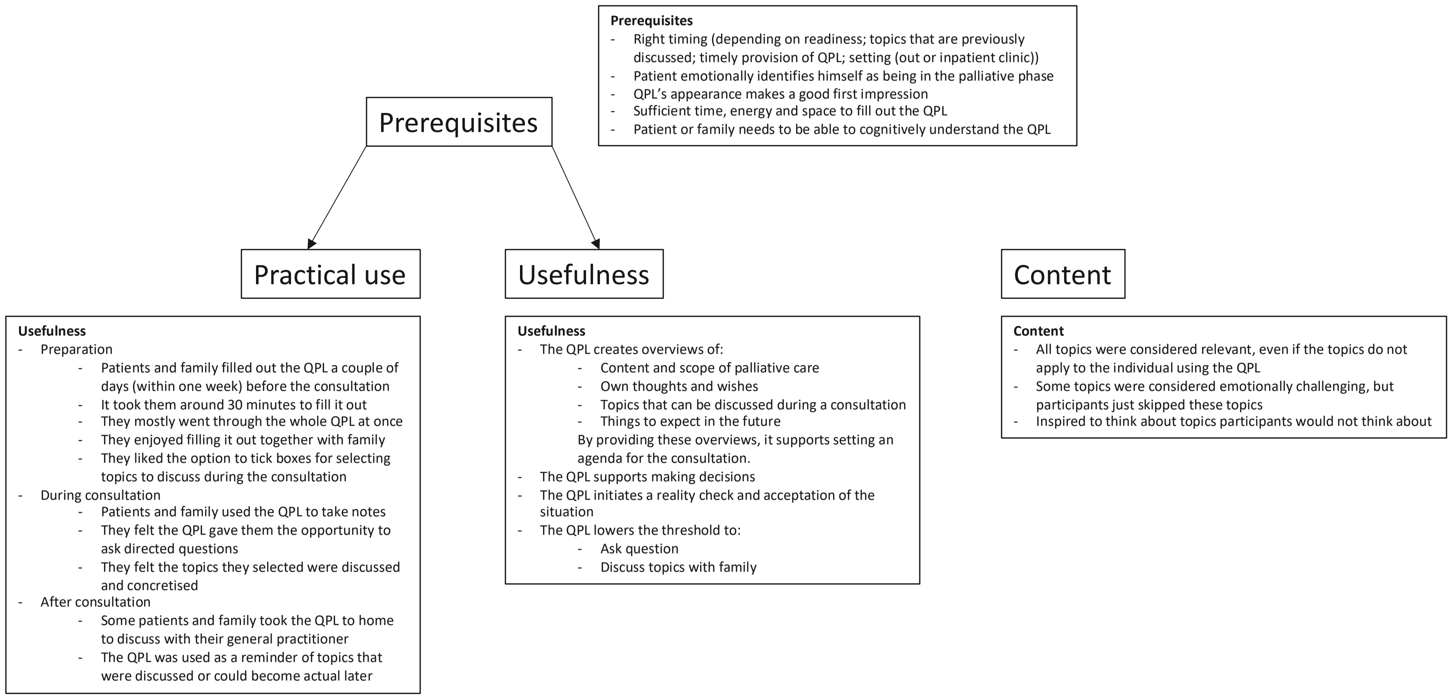
[a] *25 patients had used the question prompt list; 7 had not.*

Supplement 4

Leiden Guide on Palliative Care 2018

To improve comprehensibility, the wording of the Leiden Guide on Palliative Care was simplified and the lay-out was adapted according to participants' suggestions (Table 4). Questions were added and placed next to a topic so that each topic is accompanied by at least one question. The final version comprised nine categories with 43 topics and 133 questions (Supplement 6). In addition, we wrote an instruction leaflet for healthcare providers to facilitate the use of the QPL and to optimize palliative care consultations (Supplement 7).

Supplement 5



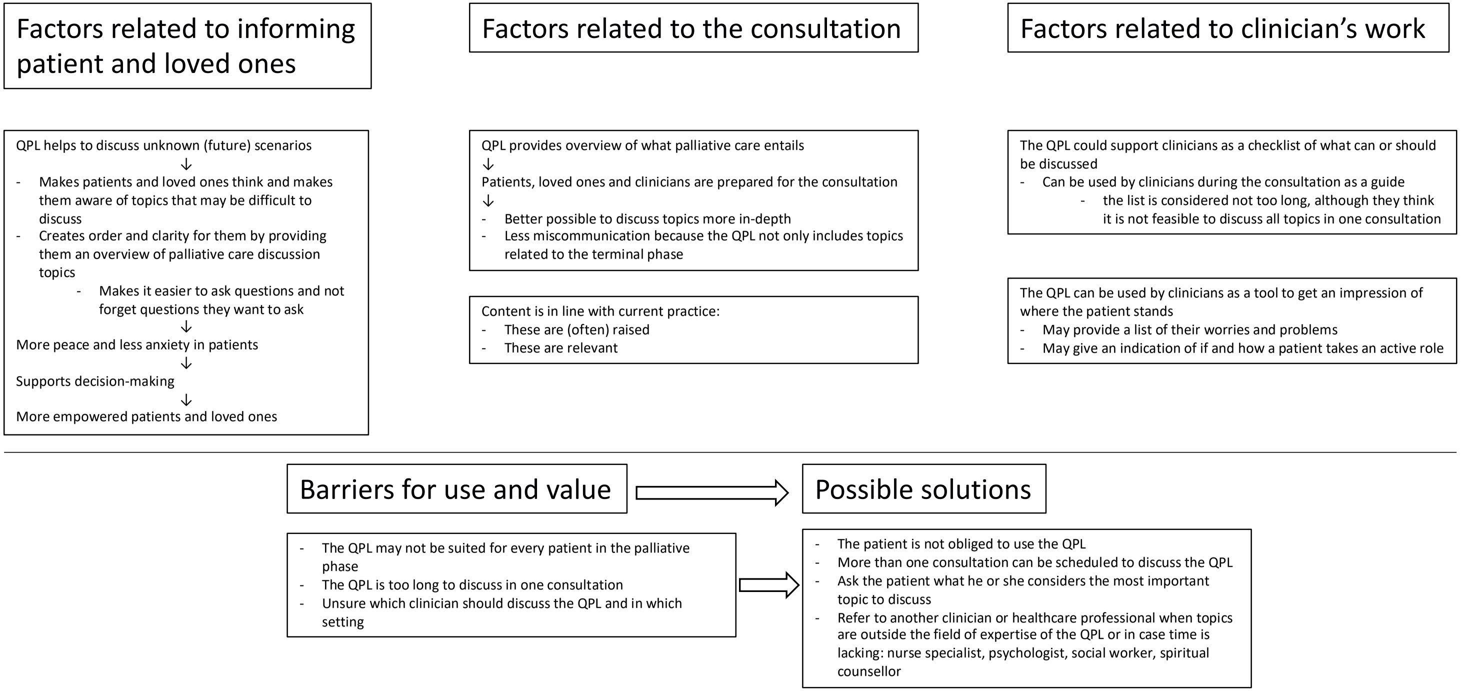
Prerequisites
- Right timing (depending on readiness; topics that are previously discussed; timely provision of QPL; setting (out or inpatient clinic))
- Patient emotionally identifies himself as being in the palliative phase
- QPL's appearance makes a good first impression
- Sufficient time, energy and space to fill out the QPL
- Patient or family needs to be able to cognitively understand the QPL

Usefulness
- Preparation
    - Patients and family filled out the QPL a couple of days (within one week) before the consultation
    - It took them around 30 minutes to fill it out
    - They mostly went through the whole QPL at once
    - They enjoyed filling it out together with family
    - They liked the option to tick boxes for selecting topics to discuss during the consultation
- During consultation
    - Patients and family used the QPL to take notes
    - They felt the QPL gave them the opportunity to ask directed questions
    - They felt the topics they selected were discussed and concretised
- After consultation
    - Some patients and family took the QPL to home to discuss with their general practitioner
    - The QPL was used as a reminder of topics that were discussed or could become actual later

Usefulness
- The QPL creates overviews of:
    - Content and scope of palliative care
    - Own thoughts and wishes
    - Topics that can be discussed during a consultation
    - Things to expect in the future

    By providing these overviews, it supports setting an agenda for the consultation.
- The QPL supports making decisions
- The QPL initiates a reality check and acceptation of the situation
- The QPL lowers the threshold to:
    - Ask question
    - Discuss topics with family

Content
- All topics were considered relevant, even if the topics do not apply to the individual using the QPL
- Some topics were considered emotionally challenging, but participants just skipped these topics
- Inspired to think about topics participants would not think about



Factors related to informing patient and loved ones

QPL helps to discuss unknown (future) scenarios
↓
- Makes patients and loved ones think and makes them aware of topics that may be difficult to discuss
- Creates order and clarity for them by providing them an overview of palliative care discussion topics
    - Makes it easier to ask questions and not forget questions they want to ask

↓
More peace and less anxiety in patients
↓
Supports decision-making
↓
More empowered patients and loved ones

Factors related to the consultation

QPL provides overview of what palliative care entails
↓
Patients, loved ones and clinicians are prepared for the consultation
↓
- Better possible to discuss topics more in-depth
- Less miscommunication because the QPL not only includes topics related to the terminal phase

Content is in line with current practice:
- These are (often) raised
- These are relevant

Factors related to clinician's work

The QPL could support clinicians as a checklist of what can or should be discussed
- Can be used by clinicians during the consultation as a guide
    - the list is considered not too long, although they think it is not feasible to discuss all topics in one consultation

The QPL can be used by clinicians as a tool to get an impression of where the patient stands
- May provide a list of their worries and problems
- May give an indication of if and how a patient takes an active role

Barriers for use and value

- The QPL may not be suited for every patient in the palliative phase
- The QPL is too long to discuss in one consultation
- Unsure which clinician should discuss the QPL and in which setting

Possible solutions

- The patient is not obliged to use the QPL
- More than one consultation can be scheduled to discuss the QPL
- Ask the patient what he or she considers the most important topic to discuss
- Refer to another clinician or healthcare professional when topics are outside the field of expertise of the QPL or in case time is lacking: nurse specialist, psychologist, social worker, spiritual counsellor

Supplement 6

Leiden Guide on Palliative Care 2018

LUMC Expertisecentrum
Palliatieve Zorg

LEIDSE GESPREKSHULP PALLIATIEVE ZORG[1]

De Leidse Gesprekshulp Palliatieve Zorg (LGP) geeft een overzicht van mogelijke klachten, problemen, gespreksonderwerpen en vragen van patiënten die ongeneeslijk ziek zijn. De gespreksonderwerpen en vragen zijn samen met patiënten en naasten gekozen.

De LGP kan u helpen belangrijke onderwerpen voor uw gesprek met de consulent van het Palliatief Advies Team te benoemen. We vragen u daarom ter voorbereiding op uw gesprek de LGP in te vullen. Als u vindt dat sommige vragen niet op u van toepassing zijn, kunt u deze vragen overslaan.

Het invullen van de LGP kost ongeveer 20 minuten. Ook als u weinig tijd hebt of erg moe bent, vragen we u in ieder geval deel 1 in te vullen.

Tot ziens bij uw gesprek.

Uw gegevens:

Naam ____________________
Geboortedatum ___ - ___ - ___
Datum ___ - ___ - ___

---

[1] Versie 3.0 2018

DEEL 1: MOGELIJKE KLACHTEN EN PROBLEMEN

Utrecht Symptoom Dagboek 4-Dimensioneel (USD-4D2)

Onderstaande vragen gaan over lichamelijke en emotionele klachten en problemen. Met een cijfer van 0 tot 10 kunt u aangeven hoeveel last u heeft. 0 = afwezig 10 = ergst denkbaar.

Ik heb op dit moment:												
geen pijn	0	1	2	3	4	5	6	7	8	9	10	erg veel pijn
geen	0	1	2	3	4	5	6	7	8	9	10	erg veel slaapproblemen slaapproblemen
geen droge mond	0	1	2	3	4	5	6	7	8	9	10	erge droge mond
geen slikklachten	0	1	2	3	4	5	6	7	8	9	10	erg veel slikklachten
goede eetlust	0	1	2	3	4	5	6	7	8	9	10	geen eetlust
goede ontlasting	0	1	2	3	4	5	6	7	8	9	10	geen ontlasting

Ik voel me op dit moment:												
niet misselijk	0	1	2	3	4	5	6	7	8	9	10	erg misselijk
niet benauwd	0	1	2	3	4	5	6	7	8	9	10	erg benauwd
niet moe	0	1	2	3	4	5	6	7	8	9	10	erg moe
niet angstig	0	1	2	3	4	5	6	7	8	9	10	erg angstig
niet somber	0	1	2	3	4	5	6	7	8	9	10	erg somber

Welke klacht(en) moet(en) wat u betreft als eerste worden opgelost?

Onderstaande vragen gaan over uw draagkracht en uw gedachten over het levenseinde. Als u vindt dat de vragen niet op u van toepassing zijn, kunt u deze vragen overslaan.

Ik voel me op dit moment:												
goed	0	1	2	3	4	5	6	7	8	9	10	slecht
Het leven heeft voor mij op dit moment:												
veel waarde	0	1	2	3	4	5	6	7	8	9	10	geen waarde
Ik kom toe aan mijzelf												
ja	0	1	2	3	4	5	6	7	8	9	10	helemaal niet
Ik kan wat me overkomt dragen												
ja	0	1	2	3	4	5	6	7	8	9	10	helemaal niet
Ik voel mij in balans over mijn leven												
ja	0	1	2	3	4	5	6	7	8	9	10	helemaal niet

Verder wil ik nog graag laten weten dat……

1. ……
2. ……

DEEL 2: MOGELIJKE GESPREKSONDERWERPEN EN VRAGEN

Lichamelijke klachten	***Mogelijke vragen***
Pijn	o Hoe kan ik minder pijn krijgen? o Kan ik pijn voorkomen? o Zijn er (andere) pijnstillers voor mij?
Benauwdheid	o Hoe kan het dat ik zo benauwd ben? o Wat kan ik tegen benauwdheid doen?
Klachten van de mond	o Wat kan ik doen als ik last heb van een droge mond? o Wat kan ik doen als ik moeilijk kan slikken? o Wat kan ik doen als ik pijn heb in mijn mond?
Eetlust	o Waardoor heb ik minder trek in eten? o Wat kan ik doen om meer zin in eten te krijgen? o Hoe voorkom ik dat ik afval? o Wat kan ik het beste eten? o Kan een diëtiste mij helpen?
Misselijkheid en braken	o Waardoor wordt mijn misselijkheid veroorzaakt? o Zijn er medicijnen tegen misselijkheid?
Problemen met de ontlasting	o Wat kan ik doen aan te harde of te zachte ontlasting? o Waardoor wordt mijn ontlastingspatroon beïnvloed? o Hoe gebruik ik de medicijnen voor de ontlasting?
Vermoeidheid	o Ik ben erg moe, hoe ga ik hier mee om? o Hoe verdeel ik rust en activiteit? o Wat kan ik doen om in conditie te blijven?
Slaapproblemen	o Ik slaap slecht. Wat kan ik hier aan doen? o Zijn er medicijnen om beter te slapen?
Jeuk	o Wat kan er aan jeuk gedaan worden?
Uw eigen vragen	o …….

Medicijnen	***Mogelijke vragen***
Aanspreekpunt	o Bij wie moet ik zijn met vragen over mijn medicatie? o Wie is er verantwoordelijk voor mijn medicatie?
Bijwerkingen	o Welke bijwerkingen hebben mijn medicijnen? o Hoe groot is de kans dat ik bijwerkingen krijg? o Ik heb last van bijwerkingen. Wat kan ik hier aan doen?
Innemen van medicijnen	o Op welke tijden kan ik mijn medicijnen innemen? o Hoe kan ik mijn medicijnen het beste innemen? o Welke medicijnen heb ik niet meer nodig? o Zijn er andere mogelijkheden als ik mijn medicijnen niet meer kan slikken?

Medicijnen	***Mogelijke vragen***
Morfine-achtige medicijnen	o Wat zijn de bijwerkingen van morfine? o Mag ik autorijden met morfine? o Kan ik stoppen met morfine als mijn pijn over is?
Uw eigen vragen	o …….

Behandelingen	***Mogelijke vragen***
Kwaliteit van leven	o Wat is de invloed van de behandeling op mijn kwaliteit van leven? o Hoe kan ik zorgen dat mijn klachten zo min mogelijk invloed hebben op mijn leven?
Keuzes over de huidige behandeling	o Waar vind ik betrouwbare informatie over behandeling? o Wat kan er gedaan worden als ik ervoor kies om de ziekte niet meer te laten behandelen? o Wie kan mij helpen bij beslissingen over de behandeling van mijn ziekte?
Uw eigen vragen	o …….

Persoonlijke aspecten	***Mogelijke vragen***
Omgaan met ziekte	o Hoe combineer ik ziek zijn met werk, school of hobby's? o Met wie kan ik praten als ik moeite heb met omgaan met ziek zijn? o Hoe kan ik omgaan met lichamelijke of geestelijke veranderingen door de ziekte? o Wie kan mij helpen met mijn zorgen? o Waar kan ik ervaringen delen met andere patiënten?
Angst	o Wie kan mij helpen als ik bang ben? o Wat kan ik doen om minder angstig te zijn?
Somberheid	o Wie kan mij helpen als ik somber ben? o Wat kan ik doen om minder somber te zijn?
Zin van het leven	o Hoe kan ik de dingen blijven doen die belangrijk voor mij zijn? o Mijn kijk op het leven en over het leven na de dood verandert. Hoe ga ik hier mee om? o Met wie kan ik praten over de zin van het leven? o Met wie kan ik praten over religieuze vragen?
Zelfstandigheid	o Hoe kan ik regie houden tijdens mijn ziekteproces? o Ik word meer afhankelijk van anderen. Hoe kan ik hier mee omgaan? o Hoe kan ik mensen om mijn heen om hulp vragen? o Hoe kan ik zo zelfstandig mogelijk blijven? o Kan ik hulp krijgen als ik ergens naar toe moet? o Kan ik hulp krijgen bij een reis of dagje-uit? o Kan een fysiotherapeut of ergotherapeut mij helpen?
Intimiteit	o Hoe zorg ik dat ik het contact met mijn partner houd? o Ik heb minder zin in knuffelen of vrijen, hoe ga ik hier mee om?
Uw eigen vragen	o …….

Toekomst	***Mogelijke vragen***
Verwachtingen	o Wat staat mij te wachten? o Welke klachten kan ik in de toekomst krijgen? Zal ik pijn krijgen? o Wat kan er gedaan worden aan klachten die ik in de toekomst krijg? o Wat kan er gezegd worden over mijn levensverwachting?

Toekomst	***Mogelijke vragen***
Keuzes in de toekomst	o Kan ik bespreken welke zorg ik in de toekomst wil, als ik dat zelf niet meer kan zeggen? Met wie bespreek ik dit? o Welke keuzes over behandeling kan ik in de toekomst maken? o Hoe leg ik vast wat ik wel of niet meer wil, zoals niet meer naar het ziekenhuis gaan?
Uw eigen vragen	o …….

Sociale aspecten	***Mogelijke vragen***
Hulp voor mijn familie of vrienden	o Waar vind ik hulp voor mijn familie, vrienden of (klein)kinderen? o Bestaan er websites voor (jonge) kinderen? o Welke websites of organisaties zijn er om mijn familie en vrienden te helpen? o Hoe leg ik kinderen uit dat ik ernstig ziek ben? o Hoe bespreek ik keuzes of gebeurtenissen die voor mij belangrijk zijn met mijn naasten?
Uw eigen vragen	o …….

Organisatie van zorg	***Mogelijke vragen***
Aanspreekpunt bij lichamelijke klachten of andere problemen	o Wie bel ik bij lichamelijke klachten? o Wie bel ik bij problemen buiten kantoortijden? o Wie bel ik als ik behoefte heb om over mijn ziekte te praten?
Huisarts	o Wat kan de huisarts voor mij doen? o Waar kan ik de huisarts voor bellen?
Ziekenhuis	o Wat kan het ziekenhuis voor mij doen? o Waar kan ik het ziekenhuis voor bellen? o Is het nog nodig om naar het ziekenhuis te gaan?
Hulpmiddelen	o Welke hulpmiddelen kan ik thuis krijgen? o Hoe kan ik hulpmiddelen voor thuis regelen? o Wie kan mij helpen met hulpmiddelen of aanpassingen in huis?
Huishoudelijke zorg	o Hoe kan ik huishoudelijke hulp regelen?
Thuiszorg	o Kan ik in de toekomst thuis zorg krijgen? o Hoe kan ik thuis zorg regelen?
Vrijwilligers	o Wat kunnen vrijwilligers voor mij doen? o Waar vind ik informatie over zorg door vrijwilligers?
Hospice zorg	o Wat is een hospice? o Welke zorg kan een hospice geven? o Wat zijn de kosten van een hospice?
Palliatief Advies Team	o Wat kan het Palliatief Advies Team voor mij doen? o Kan het Palliatief Advies Team mij helpen met het vinden van betrouwbare informatie, websites of folders?
Psychische ondersteuning	o Hoe kan psychische ondersteuning mij helpen? o Hoe kom ik in contact met psychische ondersteuning? o Kan ik ook psychische hulp aan huis krijgen?
Uw eigen vragen	o …….

Laatste levensfase	***Mogelijke vragen***
Praktische zaken rondom het levenseinde	o Wat moet ik bespreken met mijn naasten? o Hoe vind ik een manier van afscheid nemen die bij mij past? o Wie kan mij helpen een wilsverklaring op te stellen? o Hoe regel ik mijn zaken en stel ik een testament op? o Met wie kan ik praten over mijn financiële situatie? o Hoe moet ik mijn uitvaart regelen?
Verloop van de laatste fase	o Kan ik informatie krijgen over hoe de laatste weken van het leven er uitzien? o Welke zorg kan ik krijgen in de laatste periode van het leven?
Plaats van overlijden	o Kan ik zelf kiezen waar ik wil overlijden? o Welke plaats kan ik kiezen om te overlijden?
Vocht en voeding	o Wat moet ik doen als ik meer moeite krijg met eten en drinken in de laatste periode van leven? o Hoe kunnen mijn naasten mij helpen als ik meer moeite krijg met eten en drinken in de laatste periode van leven? o Is het erg als ik bijna niet eet of drink als het overlijden dichtbij is?
Palliatieve sedatie	o Wat is palliatieve sedatie? o Wanneer kom ik in aanmerking voor palliatieve sedatie? o Kan ik mijn arts vragen om palliatieve sedatie?
Euthanasie	o Wat is euthanasie? o Wanneer kom ik in aanmerking voor euthanasie? o Wie moet ik mijn euthanasiewens vertellen? o Kan ik informatie krijgen over het regelen van euthanasie?
Uw eigen vragen	o …….

Vragen van naasten of mantelzorgers	***Mogelijke vragen***
Zorg verlenen	o Hoe kan ik het beste voor mijn dierbare zorgen? Wat moet ik hiervoor kunnen? Waar kan ik hulp bij krijgen? o Wat moet ik doen als hij/zij weinig wil eten of drinken? o Zal hij/zij door minder te eten of drinken korter leven? o Kan het helpen voor de zorg als ik meer vertel over de persoonlijkheid en cultuur van mijn dierbare?
Ondersteuning	o Hoe houd ik het als mantelzorger vol? o Waar kan ik hulp vragen als de zorg te veel voor mij wordt? Wat zijn de mogelijkheden? o Waar vraag ik hulp als ik het emotioneel moeilijk heb? o Bij wie geef ik aan dat er meer zorg nodig is? o Wie stel ik vragen over de zorg die mijn dierbare krijgt? o Waar kan ik aan zien of het moment van overlijden dichterbij komt?
Nazorg	o Hoe ga ik straks om met het verlies van mijn dierbare? o Kan ik hulp krijgen als mijn dierbare er niet meer is? o Waar kan ik hulp krijgen bij het verwerken van mijn verlies? o Is een nagesprek met de zorgverlener mogelijk?
Uw eigen vragen	o …….

Eigen onderwerpen en vragen

………

………

………

………

Heeft u nog vragen?
Neem contact op met het Palliatief Advies Team:

Telefoon	071 52 61916 (tijdens kantooruren)
E-mail	palliatievezorg@lumc.nl

Supplement 7

LEIDEN GUIDE ON PALLIATIVE CARE:

Guide for clinicians

Instrument can be requested by e-mailing with palliatievezorg@lumc.nl

What is the Leiden Palliative Care Conversation Tool?

The Leiden Guide on Palliative Care (LGP) is a list of possible topics and questions that can support patients and/or their loved ones in preparing for a conversation about palliative care and end-of-life decisions. It can help them formulate the questions they want to discuss. The topics and questions of the LGP were chosen together with patients and their loved ones.

The LGP consists of:

1. An Utrecht Symptom Diary 4-Dimensional (USD-4D) to indicate symptom burden and quality of life;
2. A list of topics and questions on themes within palliative care about:

a. Physical complaints
b. Medications
c. Treatments
d. Personal aspects
e. Social aspects
f. Future
g. Organization of care
h. Last stage of life
i. Questions from loved ones or informal caregivers

Space has also been left open for patients and family to add their own questions.

Who is the target population for the LGP?

- The LGP is intended for any patient in the palliative phase and his/her loved ones.
- If the LGP cannot be completed by the patient and loved ones together (e.g., because the patient is too tired, has cognitive problems, or is low-literate), a loved one can complete the LGP.

When do I introduce the LGP?

- The LGP can be used at any time within the palliative phase, from the time a person is diagnosed with an incurable disease.
- The LGP is used to prepare for conversations of physicians and nurses (both 1st and 2nd line) with patients in the palliative phase. For example, conversations about symptoms (what bothers them based on the results of the USD), about end-of-life decisions or other expected problems/questions about the course of the illness based on the subject list. The earlier these discussions are held in the course of the disease, the more useful they can be for the patient.

What use is the LGP to me as a clinician?

- It provides an overview of possible topics to discuss in the palliative phase.
- It lowers the threshold to bring up topics that are difficult to discuss.
- How the patient has filled out the LGP can provide insight into

o Dealing with the disease,
o The ease with which the patient can talk about the illness and its consequences,
o Whether the patient needs little or a lot of information,
o Whether the patient prefers not to discuss specific themes. For example, there are patients who say ‘not applicable’ when asked about the dying phase.

How do I introduce the LGP to my patient and his/her loved ones?

- The LGP can be emotionally challenging for patients and loved ones. Therefore, when handing over the LGP, it is wise to give a brief verbal explanation. For patients who have a lot of difficulty talking about the end of life, it may be more appropriate to only introduce the USD and leave the topic list for now. Give the patient enough time to complete the LGP by giving it to them well in advance of the consultation.

Important points to tell patients when introducing the LGP are:

- Palliative care is more than care in the dying phase and focuses primarily on quality of life.
- The LGP is a list of common discussion topics and possible questions from patients in the palliative phase and their loved ones.
- The LGP is a tool that allows the patient to gain insight into his/her questions and issues that may become important in the coming period.
- There are questions in the LGP that are not (yet) applicable. Ask the patient to tick only those questions that are appropriate for him/her.
- The LGP is used as a guide for the discussion with the clinician. In this way, the patient controls which topics he does or does not want to discuss.

- Completing the LGP takes approximately 20 minutes. For many patients it is pleasant to do this together with a loved one. In this way, it can also enhance the conversation between patient and loved ones.

How do I use the LGP during my consultation?

- Time is needed to discuss the LGP with patients and loved ones, usually at least 1 hour. If necessary, the topics can also be discussed in several sessions.
- Start the discussion by asking what the patient considers the most important topic to be discussed. Then the other topics can be discussed point by point.
- Patients often want to obtain a future view of their disease, their symptoms, their prognosis and their end of life. Therefore, it is advisable to discuss possible so-called “future scenarios” from each complaint and possibly record them in a so-called roadmap.
- If themes or questions do not fall within your area of expertise, it may be useful to refer the patient and his relatives, for example, to a spiritual counselor or the palliative care team.

CHAPTER 8

General discussion

This chapter consists of five parts. Part 1 provides the main findings of the studies presented in this thesis. Part 2 reflects on the methodologies used in our studies. Part 3 describes the implications of the outcomes of this thesis regarding a proactive approach in palliative care. Part 4 includes recommendations for future research and Part 5 provides recommendations for education, clinical practice, and policy.

8.1 MAIN FINDINGS

Objective 1: To assess the extent to which end-of-life care is taught at medical schools in the Netherlands and to find opportunities to improve Dutch medical curricula.

Chapter 2 describes a cross-sectional study assessing the extent to which end-of-life care was part of Dutch medical curricula. This study was focused on end-of-life care as essential part of palliative care. The study was conducted during the academic year of 2015-2016. A checklist including the essential domains of end-of-life care education was constructed based on literature. The study demonstrated that the national blueprint on medical education included four of the five domains of end-of-life care. One faculty taught an elective course that included all essential domains. None of the eight medical faculties taught all domains of end-of-life care; these domains were taught in the light of other courses but did not specifically address end-of-life care.

Objective 2: To explore palliative care needs and the extent of proactive care in patients with advanced cancer who visited the emergency department (ED) in the last three months of their lives.

Knowledge about problems leading to visits to the Emergency Department (ED) in patients in the last three months of their lives and about who are at high risk of approaching death is relevant in ED-triggered palliative care. In **Chapter 3**, we conducted a mortality follow-back study in 420 patients with advanced cancer who visited the ED up to three months before they died. Our study showed that their care was often still focused on disease-modification. Only a few patients had limitations on life-sustaining treatments. This may have led to a high percentage of hospitalisations and in-hospital deaths in this study. Factors associated with approaching death were lung cancer, neurologic deterioration, dyspnoea, hypercalcemia, and jaundice.

Objective 3: To describe the end-of-life trajectory and quality of care of patients with a haematological malignancy who visited the ED in the last three months of their lives, compared to patients with advanced cancer.

Patients with a haematological malignancy often receive more aggressive end-of-life care than patients with a solid tumour. Insight into cues for proactive care can help improving ED-triggered palliative care in patients with a haematological malignancy. **Chapter 4** presents a mortality follow-back study in 78 patients with a haematological malignancy and 420 patients with a solid tumour visiting the ED in the last three months of life. Before their ED-visits, patients with a haematological malignancy had less often discussed limitations on life-sustaining treatments. Since their ED-visit, patients with a haematological malignancy were more often hospitalised after their ED-visit, received more aggressive end-of-life care, and more often died in-hospital, in the intensive care unit or in the ED, compared to patients with a solid tumour.

Objective 4: To evaluate the performance of the surprise question to identify palliative care needs in patients with advanced cancer visiting the ED.

The Surprise Question (SQ), ''Would I be surprised if this patient died in the next 12 months?'', is an instrument to identify patients with palliative care needs. A meta-analysis of Downar et al. demonstrated that the SQ lacks sensitivity and may be more accurate when combined with other indicators of palliative care needs. **Chapter 5** describes an observational cohort study in 245 patients with advanced cancer visiting the ED in 2013 and 2014. The SQ had the following test characteristics: sensitivity of 89%, specificity of 40%, positive predictive value of 85%, negative predictive value of 50% and a c-index of 0.56. In patients in whom physicians would not be surprised if they died within one year, ECOG performance status 3-4 was an independent predictor for approaching death. Addition of ECOG performance status 3-4 as a second step to the SQ improved the c-index (0.65), specificity (92%) and positive predictive value (95%) at cost of sensitivity (40%) and negative predictive value (29%).

Objective 5: To explore the association between symptom burden and information needs of patients referred to a hospital palliative care consultation team using the Leiden Guide on Palliative care (LGP).

The LGP is a conversation guide on palliative care consisting of two parts. The first part comprises the Utrecht Symptom Diary, a translated and adapted Edmonton Symptom Assessment Scale.[1] The second part is a question prompt list on palliative care, a Dutch adaption of the version developed by Clayton et al.[2] The relationship between patient-reported symptom burden and information needs has not been studied before. **Chapter**

6 includes an observational study in 321 patients referred to a palliative care consultation team who had used a LGP between 2013 and 2018. We found that patients reported highest median symptom burden for *Fatigue* (7; range 4-8) and *Less appetite* (6; range 3-9). Most information needs were about *Fatigue* (68.0%), *Possibilities for managing complaints in the future* (68.0%) and *Complaints expected for the future* (67.3%). Patients had significantly more information needs about symptoms for which they reported clinically relevant burden, or which they had prioritised. However, patients who reported mild symptom burden, also regularly indicated that they wanted information about that symptom. Patients in the late palliative phase more often wanted information about how they can manage care at home or in a hospice, while patients in the early palliative phase wanted more information about how treatment can affect their quality of life.

Objective 6: To evaluate and further develop the question prompt list of the LGP to prepare the question prompt list for use by generalist palliative care clinicians.

In **Chapter 7**, we performed a mixed-methods study in 2017-2018 to evaluate use of the question prompt list of the LGP and to further develop it using 35 interviews with patients, family, and generalist clinicians and 32 audiotaped consultations. Patients, family, and clinicians regarded the question prompt list as relevant. Patients and family explained that using the question prompt list before the consultation structured their thoughts and helped them ask their questions during consultations. It supported them to regain a sense of control. Although using the question prompt list could evoke strong emotions, they indicated that their real challenge was to accept being a patient in the palliative phase. Clinicians found that the question prompt list could support them as a reminder of discussion topics. During consultations in the hospital with palliative care consultants, topics patients and family had indicated were discussed frequently, but also topics aimed at (re)organising life at home were discussed.

8.2 REFLECTIONS ON THE USED METHODOLOGIES

In **Chapter 2**, a cross-sectional study was conducted to acquire an overview of the status of education of end-of-life care in Dutch undergraduate medical curricula. A checklist including essential domains of end-of-life care education was established based on literature review to assess the national blueprint on medical education and to form structured questionnaire to send to study coordinators. Using these methods, results of this study represent the state of education on end-of-life care in Dutch medical education in the academic year of 2015-2016 making use of internationally endorsed domains. Some participants indicated it was difficult to point out which curricular parts were actually about end-of-life care. They felt that end-of-life care, if taught, seemed to be intertwined with other topics. This may have biased the results in both positive and negative directions. To minimise this effect, all respondents were interviewed about their answers in the questionnaire. Data were provided of 15 out of 16 bachelor and master curricula in the Netherlands. Unfortunately, data from one master curriculum were not provided despite repeated reminders. Since data from the 15 other curricula were collected and analysed, this study still provides a reliable overview of end-of-life care in Dutch undergraduate medical curricula in 2015-2016. All elective courses were assessed by the researchers using the checklist. Any electives that were not found in study brochures were therefore not included, but it seems unlikely any electives were missed.

In **Chapter 3** and **Chapter 4**, we performed a mortality follow-back study in patients with advanced cancer or a haematological malignancy visiting the Emergency Department (ED) in the last three months of their lives in 2011-2013. A follow-back timeframe of three months was chosen because a life-expectancy of three months or less is an indication for referral to palliative-terminal care in the Netherlands. Including patients who died up to three months after their ED-visit gives pragmatic insight into the end-of-life trajectories of these patients, and into the intensity of care provided to them. Because we collected data retrospectively, there is a risk of registration bias and unmeasured confounding. Our study design choice for a mortality follow-up back study instead of a retrospective cohort study including all visiting the ED in 2011-2013 has important consequences. Since those who did not die within 3 months were not included, analysis of risk factors for approaching death after the ED-visit are only representative for those who will eventually die within three months.

In **Chapter 5**, the performance of the Surprise Question (SQ) in patients with advanced cancer visiting the ED is evaluated using a prospective observational design. E-questionnaires including the SQ were sent to attending physicians within one working day from the patient's ED-visit. Although e-questionnaires were sent as soon as possible, there might be some recall bias from attending physicians particularly remembering patients who were sicker than other patients. Patient data were retrospectively collected from their charts, which may have introduced bias by under-registration of characteristics and symptoms. Under-registration of symptoms that are prevalent in the palliative phase is possible because these symptoms are not routinely screened in our ED.

Chapter 6 describes an observational study on symptom burden and information needs of patients referred to a hospital palliative care consultation team between 2013 and 2018 and who had used the Leiden Guide on Palliative care (LGP). In the LGP, the Utrecht

Symptom Diary precedes the question prompt list. Because of this order, patients may have indicated information needs about symptoms more frequently than information needs about other topics. This study included mostly patients with advanced cancer, reflecting a specialised setting of an academic medical centre. Therefore, caution must be taken when interpreting the results for patients with other diseases in the palliative phase. The LGP is selectively distributed by the palliative care consultants of Leiden University Medical Center, who estimate whether patients are fit enough to go through the LGP. If they already may be in the dying phase, the LGP is not handed out. This may have led to selection bias because the study lacks data from those in the dying phase and those who did not have enough energy to go through the LGP. In addition, it is possible that some patients did not receive or use the Leiden Guide because they were not emotionally ready to read about palliative care topics. Patients could decide themselves not to use (parts of) the LGP.

In **Chapter 7**, a mixed-methods research design was used to evaluate how the question prompt list of the LGP is used and could be further developed. Data from interviews with patients, family and non-specialist palliative care clinicians, and audiotaped consultations of our palliative care consultation team were included. The patients who were interviewed mostly had cancer. It is possible that patients with different diagnoses have other information needs. The included generalist (non-specialist) clinicians had not used the question prompt list before. Their responses in the interviews were therefore hypothetical and may differ from clinical practice.

8.3 IMPLICATIONS OF THE OUTCOMES OF THIS THESIS

The studies presented in this thesis address various themes within the broad scope of palliative care. The common theme explored is proactivity in palliative care, and how it can be improved. Opportunities are identified to improve a proactive approach in palliative care in good quality undergraduate medical education, empowerment of patients and family during palliative care consultations, timely identification of palliative care needs and in the use of a two-track approach for patients with unpredictable yet life-threatening diseases. This section includes four paragraphs:

1. Definition and meaning of proactive palliative care
2. Promoting knowledge and self-initiation
3. Intention to produce good results and avoid (future) problems
4. Thinking ahead to be able to act before things happen

The first paragraph explains more about what proactivity and proactive palliative care entail. The following three paragraphs elaborate on the characteristics of proactive palliative care that are derived from paragraph 1 and studied in this thesis.

8.3.1 Definition and meaning of proactive palliative care

Proactivity is an integral part of palliative care. When searching for the definition of proactivity in English dictionaries, the following definitions of '*proactivity*' can be found:

- *Taking action by causing change and not only reacting to change when it happens* (Cambridge dictionary)
- *Intending or intended to produce a good result or avoid a problem, rather than waiting until there is a problem* (American dictionary)
- *Taking action to make changes yourself rather than reacting to things that happen* (Business English dictionary)

From these definitions of proactivity, the following characteristics of a proactive person ('the actor') can be derived:

- the actor must have **knowledge and self-initiation** to act himself and **take control**.
- the actor must have an **intention** to make a change to **have good results** or to **avoid problems**;
- the actor must **think ahead** to be able to act before things happen;

The concept of proactivity is studied in-depth in management and business studies and can be regarded as a process in which goals are proactively set and strived for.[3] In health care, the concept of proactivity is not widely studied yet. Proactivity is mainly described as patient behaviour, a characteristic or behaviour of (successful) healthcare professionals and as health promotion.[4-8] In these studies, proactivity was defined as: anticipating in correcting problems before they "become insurmountable mountains"; information-seeking, advice-seeking, participating in decision-making, assertiveness towards healthcare professionals, actively taking care of one's health status, promoting health and wellbeing. 'The actor' in health care can refer to patients, their family, and clinicians.

Palliative care is deemed appropriate already early in the illness trajectory concurrent with life-prolonging treatments. Palliative care models such as illustrated by Murray et al. show that patients and family have care needs in physical, psychological, social, and spiritual domains during the whole illness trajectory (Fig.1 in Chapter 1).[9, 10] Palliative care integrated early into standard life-prolonging or even curative therapy creates the opportunity to support patients and family to express what they value in life and how they want to live their lives. In this way, appropriate care can be organised concordant with the patient and family's needs and wishes. They can timely prepare for the end of life. In scientific literature, proactive palliative care is often equated to early palliative care, and involves timely identification of patients with palliative care needs, proactive conversations about patients' and family's wishes about the end of life, patient empowerment and prevention of future problems.[11, 12] However, proactive palliative care not only refers to early palliative care, but is an appropriate approach along the whole illness trajectory. Sometimes, dependent on the illness trajectory, it is not possible to initiate palliative care early; in these cases, a 'late' proactive approach is also demanded to achieve person-centred and appropriate care.

Proactive palliative care includes actions such as goals-of-care discussions, multidimensional treatment of symptoms and supportive care of patient and family, multidisciplinary collaboration, and preventive medicine. Other aspects of proactive palliative care are communication with other healthcare providers about end-of-life issues and making and sharing proactive care plans.[13-18] Palliative care can therefore be considered as an active approach to care in the last phase of life with proactive characteristics. The 2017 Netherlands Quality Framework for Palliative Care indeed describes that one of the core values of palliative care is being proactive: *"Together with the patient and family, the physical, psychological, social and spiritual dimensions should be* ***proactively*** *assessed and documented for situations in which:*

- *normal, everyday attention is enough;*
- *there is a need for guidance or treatment;*
- *crisis intervention is necessary."*[19, 20]

In proactive palliative care, goals of care should be discussed in shared decision-making. Aligning with the 2002 World Health Organisation's definition of palliative care and the previously derived definition of proactivity, proactive palliative care has the following goals:[3, 21]

- *to produce a good result*, i.e., to improve or maintain quality of life and appropriate care.[22] Appropriate care is associated with good supportive care, care decisions including waiving or stopping treatment, sufficient symptom relief, care at home, following wishes of the patient, and effective communication (including advance care planning, right attitude, listening and informing).[23] To achieve this, palliative care should be of good quality and in line with preferences of patients and family, while taking into account the four dimensions of palliative care (psychological, social, physical and spiritual), and stimulate self-management of patients and family. To optimally benefit from palliative care, a palliative care approach should be integrated into standard care early in the disease trajectory. Along the whole illness trajectory, good quality palliative care is proactive rather than reactive. A proactive attitude is preferred to prevent problems and suffering in the (near) future.

- *to avoid (future) problems*, i.e., to avoid poor quality of the last phase of life. A poor quality of the last phase of life includes unnecessary symptom burden, caregiver burden and inappropriate care. Inappropriate care is associated with insufficient supportive care, overtreatment and insufficient symptom relief, hospital care, not following wishes of the patient, and poor communication (mainly informing insufficiently and not-listening).[23]

Taking the aforementioned concepts and definitions of proactivity and palliative care into account, the following themes can be identified, with the following recommendations articulated in this thesis:

Theme	**Subthemes addressed in this thesis**
8.3.2 Promoting knowledge and self-initiation in clinicians, patients, and family	1. Good education for undergraduate medical students 2. Patient and family empowerment
8.3.3 Intention to produce good results and avoid (future) problems	1. Quality indicators for palliative care in patients with a haematological malignancy 2. Timely identification of palliative care needs: ED-triggered palliative care in patients with advanced cancer
8.3.4. Thinking ahead to be able to act before things happen	1. A two-track approach 2. Discussing future scenarios

The next sections will discuss how the studies included in this thesis contribute to the concept of proactive palliative care, and which recommendations can be made based on this thesis.

8.3.2 Promoting knowledge and self-initiation in clinicians, and patients and family

1. Good education for undergraduate medical students

(partly adapted from de Bruin et al. NED TIJDSCHR GENEESKD. 2020;164:D4115)[24]

In the Netherlands, provision of palliative care is organised following the generalist – specialist palliative care system.[25] This means that all clinicians should have at least basic palliative care competences. These responsibilities are described in the Netherlands Quality Framework for Palliative Care 2017.[19] Furthermore, a publication in JAMA about the need for appropriate palliative care during the COVID-19 pandemic, reminded that palliative care is a human right, and that patients without curative options should not be abandoned.[26] The study in **Chapter 2** addressed undergraduate medical education.

The study demonstrates that the 2009 Dutch national blueprint on medical education insufficiently mentioned end-of-life care, and none of the formal undergraduate curricula of the Dutch medical schools in the academic year of 2015-2016 offered all essential elements of end-of-life care education. The national blueprint on medical education is authoritative for the curricula for Dutch medical faculties and should therefore at least include the essential domains of end-of-life care, which were found using a literature review. Pieters et al. found that final year medical students indicated that various topics were insufficiently addressed in their curricula and 60% of them felt unconfident in providing palliative care.[27] In March 2020, the new blueprint on medical education was published.[28] The introduction of the blueprint stated that it aims to prepare medical students for the future, including challenges of ageing populations and multimorbidity. The definition of palliative care is added, and generalist palliative care is now anchored as basic knowledge any freshly graduated physician should have.

Chapter 2 provides insight in how individual bachelor and master curricula in the Netherlands can improve their programmes so that young physicians are sufficiently prepared for clinical practice. Many efforts have been made to integrate palliative care into existing Dutch medical curricula. The Palliative care Alliance Sharing Educational tools for Medical student Competencies development (PASEMECO) project, listed six Entrustable Professional Activities (EPAs) for undergraduate medical education regarding palliative care that should be taught to all medical students.[29] These EPAs reflect which clinical activities young physicians can encounter in clinical practice. Additionally, the PASEMECO project offers an online toolbox with elements of palliative care education which are published on the Palliaweb website.[30] These elements are collected from all Dutch universities and are free to use by teachers.

This thesis only addressed undergraduate medical education. The O2PZ programme, which is supported by the Dutch government since 2019, aims at securing palliative care education at all educational levels in the Netherlands. In this programme, palliative care specialists, teachers and educationalists cooperate in developing education frameworks that provide an overview of all continuing education courses, designing and implementing education, and increasing the visibility of what is happening to optimise palliative care education.[31] In the O2PZ programme, the EPAs for undergraduate medical education formulated by the PASEMECO project are further developed and complemented.[32] Amongst many other activities, the O2PZ programme supports medical faculties in implementing palliative care education, so that their curricula meet the criteria of the blueprint.

Integration of palliative care and end-of-life care education into undergraduate medical curricula contributes to the preparation of future medical doctors to provide generalist palliative care. Promoting their knowledge and skills is a prerequisite for employing a proactive palliative care approach in clinical practice.

2. Patient and family empowerment

This paragraph demonstrates how this thesis articulates to the concept of patient empowerment as part of the person-centred care model. Proactive palliative care includes the improvement of patients and family's self-initiation: empowerment. Part of empowerment is the exploration of the values and needs of individual patients, which is also essential in person-centred care. Many definitions of person-centred or patient-centred care exist and are often used interchangeably. Little et al. identified core activities of patient-centred care:[30, 33]

- Exploring how patients experience their disease and illness, including their ideas and feelings about it, their expectations of the consultation and how their functioning is affected;
- Understanding the patient as a whole, including personal and developmental aspects and their context;
- Establishing a partnership with the patients, sharing problems, priorities, and goals of treatment, agreeing on the patient and clinician's roles, enhancing this patient-clinician relationship by sharing power and sustaining a relationship that is caring and healing;
- Promoting health, including enhancement of health, reduction of risks and the early detection of disease.

Person-centred care originates from care for people with a chronic illness, where planned care (i.e., proactive care) is preferred to reactive care because it creates more opportunities to provide appropriate care. A person-centred approach is then appropriate since the person himself is the expert of his own experience of being ill. It is patient-friendly to support them so that they can manage their needs in a way that fits their way of life and being best.[34] Person-centred care has favourable patient outcomes: patients have a better understanding of their illness, are more aware of their health and treatment options, feel more capable and confident to make decisions, and know more about symptoms.[34-36]

Person-centred care is a model of care that makes it possible to share knowledge, status, and decision-making in an equitable patient-clinician relationship. McWilliam et al. argue that these are elements that support the empowerment of patients and family.[37] The 'power' in a patient-clinician relationship changes when the 'expert' role of being ill is balanced between the clinician and the patient by sharing knowledge and experiences, and providing support. This is in line with the Netherlands Quality Framework on palliative care, which states that shared decision-making in palliative care is "*the continual process in which care is tailored to the personal situation and achievable values, wishes and needs of the patient and family*".[19] A power shift in the patient-clinician relationship towards patients and family is therefore desirable and warranted.

Patient empowerment is defined in various ways.[38] One of the definitions is that patient empowerment is "*an approach to health promotion involving patient autonomy, ensuring the patient is actively involved in their care, relying on an achievement of self-efficacy or having a sense of control in one's life*."[34] Empowering a patient can mean that the patient had been disempowered in the first place. Disempowerment may hinder their participation in decision making about the palliative phase. This experience of disempowerment corresponds with Rolland's 'crisis phase' of the 'Time Phases of Illness' in his integrative treatment model.[39] In this model, patients and family go through steps aimed at socialization to the new palliative diagnosis, which includes seven developmental tasks patient and family need to go through. Examples of these tasks are developing a meaning of the illness so that patients and family can stay in control; accepting that the illness is permanent; and learning to live with the life-limiting illness and problems associated with the illness. Patients and family are vulnerable during these developmental tasks and need advice from the clinicians to complete them. Effective communication which effectively enhances empowerment has several benefits for patients.[40] It is demonstrated that patients found they were better able to adapt to losses, including preparing for deterioration, management of personal issues and changing of priorities in life. They felt they were better capable of continuing their lives.[41]

The study in **Chapter 7** demonstrates that patients lost empowerment at the moment they found out they were in the palliative phase of their disease and that they felt more in control by using the question prompt list. They knew which issues were on their minds and which questions they wanted to ask. They felt they were better able to manage their lives because they could ask purposeful questions. As a result, the clinician's role shifts from discussing what they think are preferences of patients and family, to helping patients and family discovering their own preferences for care. **Chapter 6** shows that a question prompt list is a valuable addition to assessing symptoms, because it allows patients and family to not only indicate their current problems, but also their worries. These results show that our question prompt list enhances patient and family empowerment.

Non-specialist clinicians indicated in **Chapter 7** that using a question prompt list provides them with an overview of the information needs of patients and family and may help deepening their consultations. In this way, clinicians can give them tailored advise, so that patients and family can decide for themselves. This corresponds with Little et al.'s definition of patient-centred care: exploring patient's questions, understanding the patient within their context, enhancing the patient-clinician relationship and promoting health in line with the wishes of patients and family.[33] Furthermore, non-specialist clinicians indicated that the question prompt list can be helpful in their practice.

Because patient and family empowerment is desirable and warranted, the use of a question prompt list in palliative care is recommended. A question prompt list supports a proactive palliative care approach from a person-centred perspective, given that patient-related and clinician-related barriers are taken into account (Chapter 7, Table 3). This thesis demonstrates that the combination of the assessment of symptom burden and the assessment of information needs provides more opportunities for a person-centred and proactive approach than assessment of symptom burden or information needs alone. Use of the Leiden Guide on Palliative Care, which includes both, is therefore recommended in discussing and organising proactive palliative care.

8.3.3. Intention to produce good results and avoid (future) problems

1. Quality indicators for palliative care in patients with a haematological malignancy

Palliative care, especially early palliative care, leads to favourable outcomes compared to standard care in patients with advanced diseases, such as improved quality of life and relief of symptom burden.[42-49] These outcomes should be the goal of investing in producing good results and avoiding (future) problems. An example of a 'problem' that should be avoided is hospitalisation in the last months of life, because this can lead to aggressive or potentially inappropriate end-of-life care.[50] Research has shown that not all end-of-life hospitalisations are necessary.[51] Hospitalisations in the last three months of life can be avoided in 24%, according to general practitioners.[52]

Indicators for aggressive end-of-life care are described in more detail in **Chapter 1**. Indicators in the study on patients with cancer described in **Chapter 4**, by Earle et al., are the following:

- Receiving chemotherapy in the last 14 days of life;
- Starting a new chemotherapy regimen in the last 30 days of life;
- >1 emergency room visit in the last month of life;
- >1 hospitalisation in the last month of life;
- Admission to the intensive care unit in the last month of life;
- Death in an acute care hospital;
- Lack of admission to hospice;
- Admission to hospice <3 days before death.[53, 54]

In **Chapter 4**, the causes of death of patients with a haematological malignancy were disease progression (46%), treatment toxicity (40%), or both (9%), illustrating this particular end-of-life trajectory. These illness trajectories are often unpredictable with a sudden decline while patients are undergoing intensive treatment with curative intent. Because of the typical illness trajectory, one may wonder whether the common indicators of Earle et al. are appropriate for measuring the quality of end-of-life care in patients with a haematological malignancy.[55] Haematologists do not necessarily believe hospice admission early in the illness trajectory is an indicator of good quality of end-of-life care, because hospices or hospice care often cannot provide blood transfusions in cases of severe symptoms of anaemia, such as exhaustion, dyspnoea and bleeding.[56] More often, patients with a haematological malignancy will choose the possibility of blood transfusions over hospice care, risking of hospitalisations and admission to the ICU.[56] A study by Odejide et al. showed that haematologists found that the following quality indicators were considered acceptable by haematologists:

- Hospice admission > 7 days before death;
- No chemotherapy ≤ 14 days before death;
- No intubation in the last 30 days of life;
- No cardiopulmonary resuscitation in the last 30 days of life.[57]

These indicators for quality of care represent events that should be prevented, but do not explain what quality palliative care looks like. A two-track approach can support a proactive palliative care approach in haematology. Figure 1 in **Chapter 4** illustrates that curative care and palliative care should be concurrent because patients can have needs from both tracks. The curative track focusses on cure, whilst the palliative track focusses on the quality of life. Button et al. suggested an alternative disease trajectory model for haematological malignancies.[58] This model assumes that all patients with a haematological malignancy, no matter if the treatment is of curative or palliative intent, need a palliative care approach.

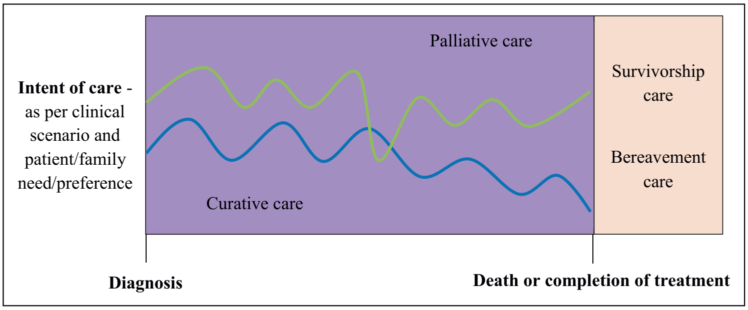


Fig. 1. Modified model of palliative care for people with a haematological malignancy. From Button E, Bolton M, Chan RJ, Chambers S, Butler J, Yates P. A palliative care model and conceptual approach suited to clinical malignant haematology. Palliative Medicine. 2019;33(5):483-485. doi:10.1177/0269216318824489[58]

The two-track approach in **Chapter 4** suggests a continuous evaluation of the goals of care. The cues for proactive care that were collected in **Chapters 3 and 4** can also be used for reviewing if the care delivered is concordant with the wishes of patients and family:

- Documentation of communication about the condition of the patient between a hospital clinician or palliative care specialist and the general practitioner of the patient. This communication could have occurred via a letter, telephone call or transfer notes.
- Documentation of proactive care plans, which could be the following documents:
    - Care plans for anticipating future symptoms or worsening symptoms;
    - Care plans directed at informing the general practitioner;
    - Care plans written by the palliative care consultation team;
    - Referrals to the palliative care consultation team.
- Documentation of limitations on life-sustaining treatments (i.e., no resuscitation, no ventilation, no admission to the intensive care unit).

In summary, commonly used indicators for quality of end-of-life cancer care may not be applicable for patients with a haematological malignancy and do not explain what quality proactive palliative care entails. Goal concordance, which is part of the two-track approach, can be an indicator of proactive palliative care and can be found in documentation in patient records.

2. Timely identification of palliative care needs: ED-triggered palliative care in patients with advanced cancer

In order to produce good results and avoid (future) problems (for definition, see 8.3.1), patients with palliative care needs should be timely identified. Early identification of palliative care needs can be difficult. Patients use acute healthcare resources more often in the last phase of life. Reasons for admission to an Emergency Department (ED) or hospital ward include serious symptom burden, not being able to manage at home, caregiver burden or lacking resources in the community setting.[59-62] Reaching out for acute medical help in the last phase of life may indicate disease progression and urgent palliative care needs. Because of this, events such as hospitalisations and ED-visits can function as triggers to consider if the patient can benefit from a palliative care approach.[63-67] **Chapter 3** illustrates that ED-visits triggered initiation of discussions on and documentation of limitations on life-sustaining treatments in many of the patients visiting the ED. This thesis addresses two elements of ED-triggered palliative care for patients with advanced cancer: identification of patients with urgent palliative care needs; and estimation of the urgency of palliative care needs using the Surprise Question and poor physical performance.

In **Chapter 3**, risk factors for approaching death were identified to support identification of patients with advanced cancer visiting the ED: a diagnosis of lung cancer, neurologic deterioration, dyspnoea, hypercalcaemia, and jaundice. Together with triggers for palliative care derived from previous literature, these risk factors were integrated into a risk assessment tool.[68] The use of these triggers can support ED-clinicians in choosing actions leading to appropriate care for vulnerable patients. These actions include goals-of-care discussions, assessment of patients and family needs, referral to the preferred place with appropriate care and referral to specialist palliative care for complex problems.

Although risk assessment tools for approaching death can be useful in the ED-setting to organise appropriate care,[69-71] they are not suited for early identification of patients with palliative care needs. The study in **Chapter 5** demonstrated that the surprise question was a predictor for death within one year with a high sensitivity and positive predictive value, and can be used as a screening tool to early identify patients with palliative care needs in patients with advanced cancer visiting the ED. Specificity and c-statistic improve if poor functional status (ECOG 3 or 4) is added as a second step following the surprise question. A similar effect has been demonstrated in a study in elderly visiting the ED demonstrated that adding physician experience in working years and the PREDICT criteria, which are triggers for palliative care, to the one-year surprise question, improved the c-statistic for predicting one-year mortality.[72]

The studies presented in **Chapters 3, 4 and 5** have confirmed that ED-visits have a trigger effect. Limitations on life-sustaining treatments were often discussed after a patient visited the ED, apparently giving food for thought about what appropriate care is. The use of risk assessment tools, and combining the surprise question with functional status, can support ED-triggered, appropriate and goal-concordant palliative care.

8.3.4. Thinking ahead to be able to act before things happen

1. A two-track approach

A two-track approach assumes that a palliative care approach is concurrent with a curative care approach. Using scientific literature, including Button's model of care, and clinical experience of clinicians who care for patients with a haematological malignancy, an integrated care model has been developed that assumes that care for patients with a life-threatening illness should *not only hope for the best, but also prepare for the rest* (illustrated in **Chapter 4**, Fig. 1).[58, 73-76] Goals-of-care discussions are an essential part of both tracks. Although **Chapter 4** focusses on the illness trajectory of patients with a haematological malignancy, it is probable that a two-track approach can also support patients with other serious illnesses that may still be curable. Examples are patients suffering from stroke or transient ischemic attacks, severe infections, or patients with organ failure waiting for transplantation.

Timely initiation of a two-track approach is challenging. Known barriers to initiate palliative care conversations indicated by clinicians are, amongst others:[77-79]

- Lack of time to conduct such conversations properly
- The patient's wishes and expectations are unknown
- Difficulties dealing with the needs of family
- Wishes and expectations of immigrant patients are unknown
- End-of-life conversations can trouble the clinician-patient relationship
- Feeling uncomfortable or unprepared to conduct such conversations.

It seems that training and gaining experience in palliative care conversations can facilitate initiation of those conversations and the use of a two-track approach. After implementation of the serious illness communication programme of Paladino et al., non-specialist palliative care clinicians were more aware of the necessity to initiate serious illness conversations early.[80] They initiated conversations earlier in the illness trajectory, and conversations were more holistic and more multidimensional. They said they started to think more proactively. This study proves that the implementation of person-centred communication methods raises awareness among clinicians on the value of timely conversations about palliative care, and that these discussions are initiated earlier.

2. Discussing future scenarios

From this thesis follows that clinicians should inform their patients to empower them and that clinicians have a professional responsibility to signal, explain, and document future scenarios. According to the Netherlands quality framework for palliative care, the discussion and reporting of current and future needs and wishes should be a standard part of proactive palliative care.[19] The study in **Chapter 7** revealed that patients often want to know about the future and that they do not know what the future holds for them. They are reliant on their clinicians to provide them this information in order to regain a sense of control over their care. A two-track approach demands a proactive attitude from the clinician. However, Slort et al. found that future scenarios were not anticipated by general practitioners during end-of-life conversations.[81] Flierman et al. demonstrated that hospital clinicians sometimes wait for patients and family to express their wishes and preferences for the future, and do not initiate the topic themselves.[82]

Some clinicians in the study in **Chapter 7** mentioned that the question prompt list may support them in explaining future scenarios to patients and family. Patient-reported outcome measurements (PROMs), such as the Edmonton Symptom Assessment System (ESAS), can support communication between patients, their family, and clinicians.[83] Brooks et al. demonstrated that the ESAS helped them to identify and set priorities for treatment, and guided the conversation with the clinician.[84] Handing out a palliative care PROM to patients and family can therefore be considered as a proactive action. In **Chapter 6**, the Leiden Guide on Palliative care, which includes the Utrecht Symptom Diary (a Dutch adaptation of the ESAS) and a palliative care question prompt list, was used for data collection. The study in **Chapter 6** provides insight into which the symptoms patients and family have questions about. It seems that patients and family use the question prompt list to indicate about which symptoms they worry, such as shortness of breath and pain. It is known that symptoms that patients prioritise are not necessarily the symptoms that cause the highest burden.[85] This demonstrates that discussions about future scenarios can be tailored to the patient and family by using specific PROMs for assessment of symptom burden and information needs. **Chapter 6** demonstrates that the information needs of patients and family can differ by the phase of their illness. For example, patients whose treatment was mainly aimed at symptom management had more often information needs about managing care at home.

Discussing future scenarios is indicated and warranted: patients and family want and need to be informed about the future. The addition of the question prompt list to a symptom assessment scale supports clinicians to also ask about the worries of patients and family and to explain future scenarios.

8.4. RECOMMENDATIONS FOR FUTURE RESEARCH

Recommendations for future research following from this thesis will be addressed in three paragraphs:

1. Promoting knowledge and self-initiation in clinicians, and patients and family
2. Intention to produce good results and avoid (future) problems
3. Thinking ahead to be able to act before things happen

8.4.1 Promoting knowledge and self-initiation in clinicians, and patients and family

1. Good education for undergraduate medical students

Internationally, assessments of undergraduate medical education have resulted in implementation of end-of-life care courses or internships in the formal medical curricula. In the United Kingdom, for example, the assessment from 1983 revealed that four medical faculties did not pay any attention to end-of-life care.[86] Thereafter, the British medical curricula were changed in 1994 and 2002 and are regularly evaluated ever since.[87-89] Switzerland and Germany made similar changes.[90-92] The study described in **Chapter 2** and the studies by Pieters et al. can be considered as baseline measurements of the integration of end-of-life care and palliative care in the Dutch medical curricula.[27, 29] To evaluate the effect of curricular interventions, it is preferable to measure the actual presence, knowledge, perceived importance and confidence again after implementation. An evaluation study on the presence of palliative care in the undergraduate medical curricula could be conducted by using a questionnaire or structured interviews among curricular programmers. Next, the effect of curricular changes should be measured using the methods of Chapter 2 or Pieters et al.[27] EPAs (see 8.3.2.1), and competencies that are now added to the updated blueprint on medical education, can be used as primary outcomes in a cross-sectional survey or interview study in medical students who are about to finish their undergraduate medical studies. In this way, actual competence and experienced competence can be measured in young medical doctors, and opportunities for improvement of undergraduate education on palliative care can be identified.

2. Patient and family empowerment

Patients and family indicated in **Chapter 7** that the question prompt list of the Leiden Guide on Palliative Care (LGP) increased their sense of control. Future research should be aimed at how much the sense of control of patients and family increases after using the LGP in terms of feeling empowered to manage their illness. Self-management can be considered as the last station in person-centred care, according to Pulverenti et al.:

Fig. 2. Person-centred care improves patient empowerment, which improves self-management in patients and family. Adapted from Pulvirenti et al.[34]

Lorig defined self-management as "*learning and practicing the skills necessary to carry on an active and emotionally satisfying life in the face of a chronic condition*".[93] The main goal of self-management interventions is supporting the patient to live and achieve those outcomes he or she wishes. Dineen-Griffin et al. created a model that supports clinicians in conducting self-management interventions during consultations in a person-centred way. Essential elements of this model are:

- Provision of effective self-management support
- Theoretical base to the intervention
- Face-to-face multicomponent intervention with primary care provider
- Tailored combination of self-management supporting strategies relevant to patient needs
- Ongoing follow-up (face-to-face, telephone)

Further research should investigate whether appropriate use of a question prompt list, according to the model by Dineen-Griffin et al., not just increases patient empowerment, but also self-management. A study on improving self-management by using a question prompt list can have a randomised controlled trial design, in which one group of patients receives and discusses a question prompt list, and the second groups receives a 'standard' palliative care consultation or conversation without a question prompt list. Both groups receive person-centred care according to Dineen-Griffin's essential elements. The primary outcome would be patients and family's self-management. In this way, the value of a question prompt list on self-management of patients and family in the context of person-centred care can be determined.

A review by Wakefield et al. suggested that a patient satisfaction questionnaire may be a valuable addition to a question prompt list.[40] Further research can include the addition of patient satisfaction to the LGP, and be aimed at if this addition can improve person-centred care, patient empowerment and self-management. A study on an addition to the LGP could be an evaluation study including semi-structured interviews or questionnaires among patients and family.

Clinicians indicated in **Chapter 7** that the LGP can support palliative care consultations. However, for purposes to study whether non-specialists would support the use of the LGP, these clinicians had not used the LGP before. In advance of implementation of the LGP in several non-specialist settings, first a pilot study should be conducted among, for example, general practitioners to study the feasibility of using the LGP in their clinical practice. This pilot study can have a participatory action research (PAR) design. Using PAR, a working method can be developed using quantitative and qualitative research methodologies while improving care activities.[94] PAR includes the execution of action cycles, during which the working method can be refined, tested, and evaluated. PAR supports developing a working method in specific settings, which may be helpful in the complexity of care settings. Next, a cluster randomised trial in general practices can demonstrate whether the LGP improves 1) patient outcomes, such as quality of life, satisfaction, information needs and symptom burden, and 2) quality of palliative care and end-of-life care, using outcomes like quality indicators and goal concordance.

The LGP is mostly studied in patients with cancer. Further research involving the LGP should also include patients with non-cancer diseases to evaluate whether use of the LGP is suited in patients with a non-cancer diagnosis. This includes repeating the study presented in **Chapter 6**, which provides an oversight of symptom burden an information needs of patients of a palliative care consultation team of an academic medical centre, in another cohort of a palliative care consultation team. In this way, insight about symptom burden and information needs of patients with other illness trajectories can be provided. This study design can also be used to study symptom burden and information needs in patients in care settings other than the hospital, such as in general practice and in nursing homes.

The research suggestions described above concern the LGP, but also apply to palliative care question prompt lists in general. To support future research on question prompt lists in palliative care, McDarby et al. recently composed a research agenda concerning the use of question prompt lists in outpatient palliative care.[95] The authors state that more knowledge and insights are needed on five questions:

- which patient populations with palliative care needs will use and benefit from using a question prompt list?
- what is the right timing of providing a question prompt list and how could a question prompt list be provided best in the context of outpatient palliative care consultations?
- which patient and family outcomes are addressed by using a question prompt list in outpatient palliative care, and how are these outcomes addressed?
- which characteristics of a question prompt list on palliative care contribute to the best benefits to patients and families in outpatient palliative care?
- what are the potential benefits of using a question prompt list for palliative care clinicians and healthcare organisations?

It is possible that the answers to each research question differ for the variety of question prompt lists, care settings and patient populations. It is important to study which situations demand certain kinds of question prompt lists. Additionally, it seems plausible that the same research questions hold for the use of question prompt lists inpatient palliative care, and that the answers may differ from outpatient palliative care.

8.4.2 Intention to produce good results and avoid (future) problems

1. Quality indicators for palliative care in patients with a haematological malignancy

In paragraph 8.3.3.1 is suggested that commonly used indicators for the quality of end-of-life care may not reflect how haematologists think what quality of end-of-life care entails for their patients. To develop a list of quality indicators for end-of-life care in patients with a haematological malignancy, a study with a Delphi technique can be useful. In such a study, haematologists with an interest for palliative care or a specialisation in palliative care can be asked to make a list of priorities regarding quality end-of-life care. Such a list of indicators of quality end-of-life care in haematology can subsequently be used in an evaluation study to find opportunities for improvement of proactive palliative care. A commonly used method for the evaluation of end-of-life care is a mortality follow-back design. The follow-back period can be three months for evaluating the terminal phase of the illness trajectory, or six months or one year for more upstream evaluation of the palliative phase of the illness trajectory.[19]

Early palliative care is preferable to timely prepare patients with a (potentially) life-threatening illness and their family. However, a proactive palliative care approach can also be initiated later in the illness trajectory, which is especially imaginable in patients with illness trajectories that are difficult to predict. Kripp et al. have constructed a prediction score for approaching death consisting of low performance status (ECOG score >2), low platelet count (<90×10−9/L), opioid treatment for pain (WHO level 3), high plasma LDH (>248U/L) and low plasma albumin (<30g/L).[96] Using these predictors, three risk groups can be identified: low risk (presence of no or one predictor; median survival of 440 days); intermediate risk (two or three predictors; median survival of 63 days); and high risk (median survival of 10 days). The Kripp prediction score can support identification of patients with palliative care needs and differentiate in urgency of their needs. However, this study was conducted in patients who were admitted to a palliative care unit, suggesting that these patients were already identified as having palliative care needs. Validation of the Kripp prediction score in a prospective cohort study in patients admitted to the haematology ward is needed to know whether the Kripp prediction score can be used to identify patients with approaching death.

2. Timely identification of palliative care needs: ED-triggered palliative care in patients with advanced cancer

An ED-visit can be a trigger to initiate proactive palliative care.[65] In **Chapter 3** and **Chapter 4**, it seems that the ED-visit triggered discussions about limitations on life-sustaining treatments. A prospective cohort study in patients identified at the ED using the surprise question can provide insight into 1) whether ED-visits increase the number of documentation of goals-of-care discussions, and 2) goal concordance of care following the ED-visit.

The trigger card presented in **Chapter 3** included risk factors for approaching death in patients with advanced cancer. To validate the trigger card and to identify other predictors for approaching death, a prospective cohort study can be conducted in patients with a diagnosis of advanced cancer (without curative treatment options or with curative treatments with a substantial risk of mortality). 'Death' can be a candidate outcome measure to identify predictors for patients in the dying phase. However, 'death within three months' could be more clinically relevant in organising appropriate palliative terminal care at the place patients and their family would prefer.

Chapter 5 demonstrated that patients with advanced cancer, about whom the clinician would not be surprised if they died within one year, and who have a poor physical performance (SQ plus ECOG 3-4), can be used to differentiate in the urgency of their needs. Research should be aimed at the question whether the use of SQ plus ECOG, as described in Table 3 in **Chapter 5**, improves patient outcomes such as quality of life and symptom burden. This could be studied in an ED using SQ plus ECOG to identify patients with palliative care needs in a prospective follow-up study design including questionnaires distributed to patients after 1, 3 and 6 months, and after 1 year. After identification in the ED, a multidimensional screening of problems should take place, for example by referring to the palliative care consultation team, or by screening by ED-clinicians using the 5-SPEED (see 8.5.2.2). As part of a cluster randomised trial, these outcomes can be compared with an ED in which standard care is provided. Also, SQ plus ECOG could be used to provide insight into the outcomes of ED-triggered palliative care as a care model. The outcomes of such a study can be a multidimensional approach to symptoms and the quality of palliative or end-of-life care including goal concordance.

The study in **Chapter 5** was conducted in patients who were already admitted to the ED. SQ plus ECOG could also provide insight if asked to the admitting clinician before admission to the ED. It could trigger goals-of-care discussions before ED-admission, which can contribute to appropriate care, with or without admission. This could be studied using a prospective cohort study design, in which the SQ plus ECOG could be asked to the ordering clinician during the triage process if it concerns a patient with advanced cancer. The primary outcome can be goal concordance of care, measured from data collected from patient records, for example by using the cues for documentation of proactive palliative care from 8.3.3.1.

It is known that conducting palliative care implementation research in the ED can be challenging. George et al. found that their screening tool was considered feasible in clinical practice by 70% of the ED-clinicians; however, although the 78% of patients who were found by screening as having unmet palliative care needs, only 26% was referred to palliative care.[97, 98] Successful implementation of a multidimensional screening intervention in the ED therefore depends on the quality of the implementation process. In Leiden University Medical Center’s ED, the acutely presenting older patient (APOP) screener was carefully introduced in the workflow of this ED. The implementation strategy, which was part of a plan-do-study-act study, included acquiring information from clinicians and patients, adaptation of the screener where appropriate, development of standard operation procedures, integration into electronic patient records and an educational intervention, which all occurred pre-implementation. Already two months after implementation, 31% vs 21% (p=0.0002) received a comprehensive geriatric assessment.[99] This demonstrates that a plan-do-study-act strategy, which is part of participatory action research, can be an effective way to implement and study palliative care interventions in the ED.

8.4.3 Thinking ahead to be able to act before thing happen

1. A two-track approach

A two-track approach as described in **Chapter 4** and in paragraph 8.3.4.1 of this chapter can improve proactive care by concurrent tracks of curative care and palliative care. To develop a two-track model of care in a haematology department, a participatory action research (PAR) approach can be used. The development of a two-track model of care as a working method using PAR not only provides insight into how the model works in clinical practice, but also aims at implementing the model into daily care. It is therefore essential to make arrangements with all involved stakeholders, including the generalist palliative care responsibilities of haematology clinicians and the specialist palliative care responsibilities of palliative care consultants. These responsibilities are described by Henderson et al.[25] Additionally, haematology clinicians should be educated about generalist palliative care in the context of their responsibilities in the palliative care track.

The description of the two-track care model as a working method and how it can be implemented can support hospital wards to start working with a two-track care model. Using the quality indicators of paragraph 8.3.3.1, the quality of care can be evaluated before and after implementation of the two-track care model. The implementation should ideally be part of a cluster randomised trial, in which haematology wards of multiple hospitals are randomised to either standard care or the two-track care model. The primary outcome should be the quality of life, and potential secondary outcomes are multidimensional symptom burden, satisfaction with care and goal concordance of care.

The haematology palliative care model as described by Button (paragraph 8.3.3.1) assumes that all patients with a haematological malignancy need a palliative care approach because of the high mortality risk due to either the illness or the treatment.[58] The Button model is probably also appropriate in other illnesses that have a similar trajectory, for example aggressive but treatable carcinomas such as advanced stage melanomas, or osteosarcomas and pancreatic carcinomas that may be treated with surgery but may also have metastasized. Also non-cancer patients may have a 'haematology-like' trajectory, for example patients with serious infections acquiring intensive treatment and patients with organ failure waiting for transplantation. The aforementioned two-track care model could also be researched using PAR to develop and implement a working method for concurrent palliative care for these patients.

A two-track approach demands a proactive attitude in discussing palliative care needs. In **Chapters 3, 4 and 5**, cues for proactive palliative care were used to study the end-of-life trajectories of patients with advanced cancer or a haematological malignancy visiting the ED (see also paragraph 8.3.3.1). This list should be evaluated and complemented in a study among experts, for example by using a Delphi technique. The list with cues for proactive palliative care can be used in evaluation studies on the proactivity of palliative care, for example in a cohort study in patients identified as having palliative care needs.

2. Discussing future scenarios

The discussion of future scenarios is part of a two-track approach. **Chapter 6** has demonstrated that patients and family have information needs about symptoms and situations that are not actual yet. In **Chapter 7**, non-specialist palliative care clinicians indicated that the Leiden Guide on Palliative Care (LGP) included items that can support discussing and explaining future scenarios to patients and their family during palliative care conversations. To study if non-specialist clinicians feel supported in discussing future scenarios by using the LGP, a study can be conducted in two groups of clinicians: 1) those trained to use the LGP, and 2) those who were not trained to use the LGP. Both groups can be asked by using interviews or a questionnaire if they discuss future scenarios, and if they feel comfortable doing it. Also, for example one and six months after implementation, patient records can be searched for if discussed future scenarios are documented, and if the number of discussions is increased in the group that was trained in using the LGP.

8.5. RECOMMENDATIONS FOR EDUCATION, CLINICAL PRACTICE, AND POLICY

Recommendations for education, clinical practice, and policy following from this thesis will be addressed in three paragraphs:

1. Promoting knowledge and self-initiation in clinicians, and patients and family
2. Intention to produce good results and avoid (future) problems
3. Thinking ahead to be able to act before things happen

8.5.1 Promoting knowledge and self-initiation in clinicians, and patients and family

1. Good education for undergraduate medical students

Following the results from **Chapter 2**, addition of the five essential domains of end-of-life care education to the Dutch national blueprint on medical education was recommended. The study was one of the many efforts to improve undergraduate medical education on palliative care, including the PASEMECO and the O2PZ projects. With the revised blueprint published in 2020, generalist palliative care has become a compulsory part of the formal medical curricula in the Netherlands.

The PASEMECO toolbox and integral palliative care course are examples that can be useful for curriculum programmers and teachers to optimise the curricula.[27, 100] Among other aims (see 8.3.2.1), O2PZ is committed to supporting curriculum programmers in integrating palliative care into the packed medical curricula. In this way, palliative care education can be integrated in a way that suits the local curricula, and in coordination with curriculum programmers. It may be difficult to persuade curriculum programmers to make space for palliative care education. A suggestion to discuss with curriculum programmers is that all medical doctors should have generalist palliative care competences, because the palliative care demand will increase (see **Chapter 1**), and these generalist competences are described in the Quality framework on palliative care.[19, 20, 25]

Measuring and evaluating the quality of undergraduate medical education can result in better anchoring of palliative care in the curricula (see 8.4.1.1). Therefore, regular evaluation of undergraduate medical curricula is not only needed for research purposes, but also to guard the preparation of medical students for their future work, including generalist palliative care competences.

2. Patient and family empowerment

The Leiden Guide on Palliative Care (LGP), a palliative care conversation guide, combines assessment of symptom burden with assessment of information needs. Using feedback of patients, family and clinicians in **Chapter 7**, an instruction leaflet was developed (Supplement 7 of Chapter 7) in order to support clinicians in using the question prompt list appropriately and optimally. This instruction leaflet can be used in training and education about the empowerment of patients and family during individual conversations about palliative care. Good training in using the LGP is necessary since use of the question prompt list may evoke strong emotions in patients and family (**Chapter 7**), even though they expect to talk about difficult questions cohering to the phase of their illness.

Chapter 6 demonstrated that symptom assessment alone is not sufficient to explore what topics patients worry about. It seems that patients and family want to know more about the future and how they can manage the illness themselves. From the results of this thesis follows that the LGP can be supportive in both assessing (information) needs, and providing person-centred advice appropriate for the phase of their illness. The use of a combination of a symptom assessment with a question prompt list in clinical practice is recommended.

A side outcome of this thesis is the uncertainty patients, family, lay people, but also clinicians, may experience about what palliative care actually entails. Appropriate and sufficient education of clinicians, patients and family is essential when reflecting on the core principles of proactive palliative care:

Core principles of proactive palliative care

- Promoting knowledge and self-initiation in clinicians, patients, and family
- Intention to produce good results and avoid (future) problems
- Thinking ahead to be able to act before things happen

This thesis only included studies relevant to individual palliative care consultations. To really improve proactivity in the triad patients, family and clinicians, community-based interventions should be initiated. When this thesis was being written, the SIRE (Stichting Ideële Reclame) initiated nation-wide advertisements about talking about death on television, radio, and the internet. References to websites and other sources supporting people to get more knowledgeable about palliative care are essential nowadays to reach people. Indeed, first knowledge should be promoted before self-initiation, intention to produce good results and avoid (future) problems, and thinking ahead to be able to act before things happen, can be achieved.

8.5.2 Intention to produce good results and avoid (future) problems

1. Quality indicators for palliative care in patients with a haematological malignancy

The concept of palliative care is often explained using the model of Lynn and Adams and the model of Murray (**Chapter 1**). These models assume that the palliative phase includes a phase with disease-modifying treatment and/or symptom-directed treatment, terminal phase, and bereavement care. There are in general three illness trajectories, namely advanced cancer, organ failure and frailty, and the multidimensional needs of patients and family can change along the illness trajectory. The illness trajectory of patients with a haematological malignancy does not fit these models. The model proposed by Button et al. is more appropriate for patients with a haematological malignancy (paragraph 8.3.3.1).[58] This model can be applicable not only for patients with a haematological malignancy, but also for patients with an unpredictable illness trajectory with a substantial risk of death because of either the illness or the treatment. The Button model should be part of generalist palliative care education since it raises awareness for a concurrent palliative care track while undergoing curative treatment.

In quality improvement projects, haematology specific quality indicators should be used. In 8.4.2 is discussed how a list of validated haematology quality indicators can be derived. In addition, in aiming at a proactive and person-centred care, the outcome of a quality improvement project can be the goal concordance of treatments with the wishes of patients and family.

2. Timely identification of palliative care needs: ED-triggered palliative care in patients with advanced cancer

ED-visits can be a trigger for the initiation of palliative care and can improve the quality of life.[64, 66] Using the results in **Chapter 3**, and a report on care in the last phase of life in patients with advanced colon or lung cancer of by the Netherlands Care Institute (Zorginstituut Nederland), a trigger card was constructed that can support timely recognition of patients with advanced cancer at high risk of approaching death.[68] The trigger card supports taking directed actions in patients with urgent palliative care needs visiting the ED and can be implemented in the ED with help from a palliative care consultation team. Palliative care specialists should give instructions on how to use the trigger card, when to conduct goals-of-care discussions, and when to refer to specialist palliative care.

In **Chapter 4**, the predictive value of the surprise question (SQ) and the addition of other potential predictors for palliative care needs were studied. The SQ plus performance score of 3 or 4 according to the Eastern Cooperative Oncology Group (ECOG) can help differentiate in the urgency of palliative care needs in patients with advanced cancer. The clinical implications for using SQ plus ECOG 3-4 are summarised below (Table 1).

Table 1. Differentiating in urgency of palliative care needs in patients with advanced cancer visiting the emergency department, using the Surprise Question and functional status (using the ECOG classification), and appropriate actions

Patients with advanced cancer	Median survival	Actions
Step 1: Surprise Question		
NS	3 months	Initiate symptom-management and focus care on quality of life
Step 2: ECOG		
NS + ECOG 0-2; S	6 months	Initiate a two-track approach by complementing disease-modifying treatment with conversations about the potential end of life and the patient's wishes to prepare patients and family
NS + ECOG 3-4	1 month	Initiate end-of-life care according to the patient's wishes as soon as possible

Abbreviations: S: surprised; NS: not surprised; ECOG: Eastern Cooperative Oncology Group

After identification of patients who can benefit from a palliative care approach, they should be screened for symptoms or problems in a multidimensional way. George et al. developed a tool to screen for multidimensional palliative and end-of-life care needs in the ED, derived from a systematic review and shortened: 5-SPEED.[101, 102] (5-SPEED):[103]

1. pain management: how much are you suffering from pain?
2. home care: how much difficulty are you having getting your care needs met at home?
3. medication management: how much difficulty are you having with your medications?

4. psychological support: how much are you suffering from feeling overwhelmed?
5. goals of care: how much difficulty are you having getting medical care that fits with your goals?

Patients are instructed to score their answers to these questions on a 0-10 Likert scale. The 5-SPEED is validated for use in patients with cancer visiting the ED.[101]

8.5.3 Thinking ahead to be able to act before things happen

1. A two-track approach

In paragraph 8.4.2 is proposed that the Button illness trajectory model for patients with a haematological malignancy should be taught together with the more common used illness trajectories for patients with advanced cancer, organ failure and frailty. A two-track approach is a concrete application of the Button model. Education about the two-track approach in clinical practice can support non-specialist palliative care clinicians to discuss curative and palliative approaches to care with patients and their families. It is also possible to make arrangements with specialist palliative care clinicians, for example conducting the two-track approach together. In this case, the attending clinician can keep their role in the curative track, and the specialist palliative care clinician could be responsible for the palliative track. This may also help patients and family to bring up issues palliative care needs without having to worry that it will influence their curative treatment. It is important to note in education that initiating a palliative track is not only appropriate in patients who will certainly die soon; rather, patients with a possible life-threatening illness can have palliative care needs while undergoing intensive curative treatment. A two-track approach should be advertised as an approach that can answer the needs of these vulnerable patients.

2. Discussing future scenarios

Discussing future scenarios with patients and family is essential in providing proactive palliative care. However, current medical practice is mainly focused on the treatment of diseases (i.e., a more reactive approach). More attention should be invested in education and bedside teaching on prevention of unwanted outcomes, especially for clinicians providing generalist palliative care. A helpful model for initiating discussions about possible unfavourable outcomes in life-threatening illnesses and potentially curative treatments is the Goals of Car(e) model. Hui and Bruera used this model in an oncology clinic as part of integrated care. The Goals of Car(e) model uses a car as an analogy for the discussion of goals of care; not only the aspects of curative treatment, but also the aspects of supportive, palliative and hospice care should be discussed in order to prepare patients and family for a safe and pleasant road trip.[104]

Prevention can occur during individual consultations, but also on meso- and macro-level. The discussion about the prevention of unwanted outcomes can be initiated upfront, for example in healthy individuals: how do you wish your dying phase would look like, and what does absolutely not match how you want to die? Discussions about future scenarios can however take place at any time during an illness trajectory, since at any time unwanted outcomes can be prevented if discussed with patients and their family.

CONCLUSION

Proactive palliative care includes three core principles: promotion of knowledge and self-initiation in the triad of clinician, patient, and family; the intention to produce good results and avoid (future) problems; thinking ahead to be able to act before things happen. This chapter outlined which opportunities for improving proactive palliative care are provided by this thesis: the need for quality palliative care education for clinicians, improvement of patient and family empowerment, quality indicators for end-of-life care, timely identification of palliative care needs, and a two-track approach for timely discussions about palliative care and future scenarios.

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CHAPTER 9

Summary

This chapter includes a summary of the main findings presented in this thesis. A Dutch summary (‘Nederlandse samenvatting’) can be found in the Appendices.

CHAPTER 1. GENERAL INTRODUCTION

A palliative care approach aims to *“improve the quality of life of patients and their families facing the problem associated with a life-threatening illness or frailty, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.”*[1] Palliative care should be integrated into standard care early in the trajectory of patients with a potential life-limiting illness to timely prepare them and their family on how to continue living their lives while the end of life may be near.[2] Integrated palliative care is associated with a better quality of end-of-life care compared to standard care alone.[3-5] According to the 2018 Lancet Commission on Palliative Care and Pain Relief, serious health-related suffering will increase worldwide: in 2060, 47% of all people will die after going through serious health-related suffering.[6] This underlines the importance of appropriate and timely initiation of palliative care.

In the Netherlands, palliative care is organised according to the generalist-specialist palliative care model.[7, 8] This means that every clinician working with patients should have basic knowledge and skills in providing palliative care, and that they can ask specialist palliative care clinicians for support in complex cases. It is therefore warranted that knowledge and skills are adequately provided and acquired during (medical) education. Previous Dutch evaluations have demonstrated that 30% of the medical doctors had insufficient knowledge about pain treatment, and that 83% of the medical doctors would appreciate additional education about opioid and pain treatment and about palliative sedation.[9, 10] Knowledge and skills regarding palliative care had not been assessed in detail yet in Dutch undergraduate medical students.

Generalist palliative care clinicians should be trained in identifying patients who can benefit from a palliative care approach. This includes the recognition of ‘trigger moments’, which are events that mark deterioration or increased need of palliative care. Recognition of ‘trigger moments’ allows clinicians to consider goals of care and to discuss these with patients and family.[11] An important example trigger moment is when patients with a potentially life-limiting illness visit the Emergency Department (ED): ED-triggered palliative care. It is known that patients who had received ED-triggered palliative care had a better quality of life than patients who received standard care.[12, 13]

The Surprise Question, "Would I be surprised if this patient died within one year?", is used as an instrument to early identify patients with palliative care needs.[14] Its use as a screening tool is recommend by the Netherlands Quality Framework for Palliative Care.[2] The prognostic value of the Surprise Question in the ED had already been studied in patients with heart failure and in elderly patients.[15, 16] No studies had been conducted yet in patients with advanced cancer visiting the ED.

After identification of patients who may benefit from a palliative care approach, clinicians should assess which palliative care needs patients and their family have, in order to tailor palliative care. Comprehensive assessment includes multidimensional assessment of symptom burden and information needs. The Center of Expertise in Palliative Care of Leiden University Medical Center, the Netherlands, makes use of the Leiden Guide on Palliative Care (LGP) to guide their consultations with patients and family. The LGP exists of two parts. The first part comprises the Utrecht Symptom Diary, which is a translated and adapted Edmonton Symptom Assessment Scale.[17, 18] The Utrecht Symptom Diary is used for measuring and monitoring symptom burden in the palliative phase on numeric rating scales of 1-10 of twelve symptoms that often occur in the palliative phase. The second part is a question prompt list on palliative care, a Dutch adaption of the version developed by Clayton et al.[19] Patients and family can indicate in the question prompt list which topics and questions they wish to discuss during consultation. Patients and family who had used the question prompt list asked twice as many questions compared to those who had not.[20] Before conducting the studies included in this thesis, no Dutch question prompt list on palliative care had been evaluated. Moreover, the relationship between symptom burden and information needs, and what this could mean for initiating tailored conversations about palliative care, had not been studied before.

Appropriate education, insight into the use of trigger moments such as ED-visits, timely identification of patients in need of palliative care, and comprehensive assessment including assessment of symptom burden and information needs, are all key elements contributing to palliative care warranting a proactive approach. This thesis aims at identifying opportunities to improve patient-centred and proactive palliative care. The research objectives of the studies in this thesis were the following:

1. To assess the extent to which end-of-life care is taught at medical schools in the Netherlands and to find opportunities to improve Dutch medical curricula.
2. To explore palliative care needs and the extent of proactive care in patients with advanced cancer who visited the emergency department (ED) in the last three months of their lives.

3. To describe the end-of-life trajectory and quality of care of patients with a haematological malignancy who visited the ED in the last three months of their lives, compared to patients with advanced cancer.
4. To evaluate the performance of the surprise question to identify palliative care needs in patients with advanced cancer visiting the ED.
5. To explore the association between symptom burden and information needs of patients referred to a hospital palliative care consultation team using the Leiden Guide on Palliative care (LGP).
6. To evaluate and further develop the question prompt list of the LGP to prepare the question prompt list for use by generalist palliative care clinicians.

CHAPTER 2. END-OF-LIFE CARE IN THE DUTCH MEDICAL CURRICULA

This chapter describes a cross-sectional study assessing the extent to which end-of-life care was part of Dutch medical curricula. The focus on end-of-life care was chosen because it can be considered as essential part of palliative care. The study was conducted during the academic year of 2015-2016. A checklist including the essential domains of end-of-life care education was constructed based on scientific literature. The checklist was used to assess the Dutch national blueprint on medical education[21] and the Dutch medical curricula of the eight medical faculties in the Netherlands. The assessed education included eight bachelor studies, eight master studies and elective courses. Study coordinators of bachelor and master curricula were approached to fill out a questionnaire derived from the checklist and were interviewed afterwards to acquire explanation on their answers in the questionnaire. The study guides of all medical faculties were used to assess the electives. The blueprint included four of the five domains of end-of-life care. None of the eight medical faculties taught all domains specifically on end-of-life care. Most attention was given to psychological, sociological, cultural and spiritual aspects; communication and conversational techniques; and juridical and ethical aspects. One faculty taught an elective course that included all essential aspects of the international standards. We concluded that to improve education on end-of-life care, the five essential domains should be added to the Dutch national blueprint on medical education, which was due for revision in 2019. Additionally, medical faculties should review their curricula and offer end-of-life care as compulsory part of the medical curricula to prepare medical students for their future medical practice.

CHAPTER 3. PALLIATIVE CARE NEEDS OF ADVANCED CANCER PATIENTS IN THE EMERGENCY DEPARTMENT AT THE END OF LIFE: AN OBSERVATIONAL COHORT STUDY

Insight in the end-of-life trajectories of patients with advanced cancer visiting the Emergency Department (ED) is of added value in the context of ED-triggered palliative care. Chapter 3 describes a mortality follow-back study in 420 patients with advanced cancer who visited the ED up to three months before they died. This study showed that patients with advanced cancer often visited the ED while their care was still focused on disease modification. Only a few patients had limitations on life-sustaining treatments. This may have led to a high percentage of hospitalisations and in-hospital deaths in this study. Factors associated with approaching death were lung cancer, neurologic deterioration, dyspnoea, hypercalcemia, and jaundice. We concluded that timely recognition of patients at high risk of approaching death can improve end-of-life care in patients with advanced cancer. To facilitate timely recognition, a flowchart was constructed which supports taking directed actions in patients with advanced cancer and urgent palliative care needs in the ED.

CHAPTER 4. END-OF-LIFE TRAJECTORIES OF PATIENTS WITH HAEMATOLOGICAL MALIGNANCIES AND PATIENTS WITH ADVANCED SOLID TUMOURS VISITING THE EMERGENCY DEPARTMENT: THE NEED FOR A PROACTIVE INTEGRATED CARE APPROACH

ED-triggered palliative care can avoid potentially inappropriate end-of-life care.[12, 13] Patients with a haematological malignancy more frequently receive aggressive end-of-life care than patients with a solid tumour.[22] Insight into cues for proactive care can help improving ED-triggered palliative care in patients with a haematological malignancy. Chapter 4 presents a mortality follow-back study in 78 patients with a haematological malignancy and 420 patients with a solid tumour visiting the ED in the last three months of life. The aim was to compare the end-of-life trajectories and quality of end-of-life care between these patients using five of Earl et al.'s quality indicators of end-of-life care: intensive anticancer treatment <3 months, ED visits <6 months, in-hospital death, death in the intensive care unit (ICU), and in-hospice death. Cues for proactive care were 1) communication about the patient's condition between a hospital clinician or palliative care consultation team and the patient's general practitioner; 2) proactive care plans; 3) and limitations on life-sustaining treatments before the current ED-visit. Before their ED-visits, patients with a haematological malignancy had less frequently discussed limitations on life-sustaining treatments than patients with a solid tumour. Since their ED-visit, patients with a haematological malignancy received more aggressive end-of-life care and were more frequently hospitalized after their ED-visit. They died more frequently in-hospital, in the intensive care unit or in the ED. To aid both patients and ED-staff, we recommend implementing a two-track approach, a care model for early integration of palliative care concurrent with curative haematological treatment. The two-track approach aims at preparing patients with a haematological malignancy for death as a possible outcome of either their life-threatening disease or heavy treatment in a timely matter, when they can still express their wishes.

CHAPTER 5. SURPRISE QUESTION AND PERFORMANCE STATUS INDICATE URGENCY OF PALLIATIVE CARE NEEDS IN PATIENTS WITH ADVANCED CANCER AT THE EMERGENCY DEPARTMENT: AN OBSERVATIONAL COHORT STUDY

The Surprise Question (SQ), ‘‘Would I be surprised if this patient died within one year?’’, is an instrument to identify patients with palliative care needs.[14] The SQ is asked and answered by the clinician. An “not surprised” (NS)-answer is indicative for potential palliative care needs, which should be further assessed. A meta-analysis by Downar et al. demonstrated that SQ may not be a sufficient screening tool for death within one year in the overall population of patients with advanced cancer.[23] It lacked sensitivity and, therefore, under-estimated the number of patients with palliative care needs. The SQ may be more accurate combined with other indicators of palliative care needs, such as symptoms prevalent in the palliative phase, performance status, and indicators of increased utilization of formal and informal care. Chapter 5 includes an observational cohort study in 245 patients with advanced cancer visiting the ED in 2013 and 2014 to evaluate the test characteristics of the SQ. The addition of other clinical factors predictive of death was studied to find if these can improve the SQ’s test performance. The results show that the SQ had the following test characteristics: sensitivity of 89%, specificity of 40%, positive predictive value of 85%, negative predictive value of 50% and a c-index of 0.56. In patients in whom physicians would not be surprised if they died within one year, ECOG performance status 3-4 was an independent predictor for approaching death. Addition of ECOG performance status 3-4 as a second step to the SQ improved the c-index (0.65), specificity (92%) and positive predictive value (95%) at cost of sensitivity (40%) and negative predictive value (29%). Performance status can be a valuable addition to the SQ to differentiate in prognosis and thus in urgency of palliative care needs. In the ED, the combination of first, the SQ, and second, performance status, can function as a trigger to start palliative care according to patient’s wishes. A model including the SQ and performance score was constructed to support which actions are appropriate for which urgency of palliative care needs in patients with advanced cancer visiting the ED.

CHAPTER 6. ASSESSMENT OF PATIENT SYMPTOM BURDEN AND INFORMATION NEEDS HELPS TAILORING PALLIATIVE CARE CONSULTATIONS: AN OBSERVATIONAL STUDY

We performed an observational study in 321 patients referred to a palliative care consultation team who had used a LGP between 2013 and 2018 to provide insight into the relationship between patient-reported symptom burden and information needs (Chapter 6). The secondary aim was to study the relationship between palliative phase (disease-modifying versus symptom-management), and symptom burden and information needs. Most patients in this study had a diagnosis of cancer. Patients reported highest median symptom burden for *Fatigue* and *Less appetite*. Most information needs were about *Fatigue*, *Possibilities for managing complaints in the future* and *Complaints expected for the future*. Patients had more information needs about symptoms for which they reported clinically relevant burden, or which they had prioritised. However, patients who reported mild symptom burden, also regularly indicated they wanted information about that symptom. Patients in the symptom-management phase more often wanted information about how they could manage care at home or in a hospice, while patients in the disease-modifying phase wanted more information about how treatment could affect their quality of life. This study showed that assessment of symptom burden alone is not sufficient to explore about which topics patients need more information or about which they worry.

CHAPTER 7. NON-SPECIALIST PALLIATIVE CARE - QUESTION PROMPT LIST PREPARATION: PATIENT, FAMILY AND CLINICIAN EXPERIENCES.

Chapter 7 is a mixed-methods study performed in 2017-2018 to evaluate the use of the question prompt list of the LGP and to further develop it. Using 35 interviews (18 with patients and family, and 17 with clinicians), the use of the question prompt list was evaluated. The question prompt list was further developed using their suggestions. Thirty-two consultations were audiotaped and transcribed to explore the extent to which topics that patients and family had indicated to discuss, were actually discussed during the consultation. The results show that patients, family and clinicians regarded the question prompt list as relevant, comprehensible and comprehensive. Patients and family explained that using the question prompt list before the consultation structured their thoughts and helped them ask their questions during consultations. It supported them to regain a sense of control. Although using the question prompt list could evoke strong emotions, they described that their real challenge was to accept being a patient in the palliative phase. Clinicians found that the question prompt list could support them as a reminder of discussion topics. During consultations in the hospital with palliative care consultants, topics that patients and family had indicated were discussed frequently, but also topics aimed at (re)organising life at home were discussed. Using feedback of patients, family and clinicians, the LGP was adapted and an instruction leaflet was written in order to support clinicians in using the question prompt list appropriately and optimally.

CHAPTER 8. GENERAL DISCUSSION

Chapter 8 comprises five parts. In part 1, the studies included in this thesis are summarized. Part 2 reflects on the study methods that were used. In part 3, the implication of the findings is presented using the concept of proactive palliative care. Using the definitions for 'proactivity' and 'palliative care', three core principles of proactive palliative care can be identified:

- promotion of knowledge and self-initiation in the triad of patient, family and clinician;
- the intention to produce good results and avoid (future) problems;
- thinking ahead to be able to act before things happen.

This thesis describes how knowledge and self-initiation of the triad patients, their family and clinicians can be promoted. Medical students should be provided sufficient education to prepare them for their clinical practice, which includes patients in the last phase of their lives. Conversation guides such as the Leiden Guide on Palliative Care empower patients and family, which contributes to their knowledge and self-initiation.

To have the intention to produce good results and avoid (future) problems, clinicians should have knowledge about what cues and indicators for good quality and proactive palliative are. Indicators for quality and proactive palliative care are illustrated using the example of patients with a haematological malignancy. Quality and proactive palliative care include early identification of patients visiting the Emergency Department (ED). An ED-visit can be a trigger to discuss goals of care and recognition of this trigger-function supports appropriate care.

Using a two-track approach and discussing future scenarios are key components in 'thinking ahead to be able to act before things happen'. Person-centred communication methods and conversation guides can support using a two-track approach and discussing future scenarios.

The chapter further provides, from the core principles of proactive palliative care, a number of recommendations for further research (part 4) and for education, clinical practice, and policy (part 5).

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APPENDICES

NEDERLANDSE SAMENVATTING

MOGELIJKHEDEN TOT VERBETERING VAN PALLIATIEVE ZORG: OP WEG NAAR EEN MEER PATIËNTGERICHTE EN PROACTIEVE AANPAK

HOOFDSTUK 1. ALGEMENE INTRODUCTIE

De palliatieve zorgbenadering is gericht op "*het verbeteren van de kwaliteit van leven van patiënten en hun familie die geconfronteerd worden met een probleem dat samenhangt met een levensbedreigende ziekte of kwetsbaarheid, door het voorkomen en verlichten van lijden door middel van vroegtijdige identificatie, en deskundige beoordeling en behandeling van pijn en andere problemen van fysieke, psychosociale en spirituele aard*."[1] Om patiënten en familie tijdig voor te bereiden op het leven met het levenseinde (mogelijk) in zicht, wordt palliatieve zorg idealiter vroeg in het traject van een mogelijk levensbedreigende ziekte geïntegreerd in de standaardzorg.[2] Geïntegreerde palliatieve zorg wordt geassocieerd met een betere kwaliteit van zorg in de laatste levensfase in vergelijking met alleen standaardzorg.[3-5] Volgens het rapport van de Lancet Commission on Palliative Care and Pain Relief uit 2018 zal ernstig gezondheid gerelateerd lijden wereldwijd toenemen: in 2060 zal 47% van alle mensen overlijden na het doormaken van ernstig gezondheid gerelateerd lijden.[6] Dit onderstreept het belang van het adequaat en tijdig initiëren van palliatieve zorg.

In Nederland is palliatieve zorg georganiseerd volgens het generalist-specialist palliatieve zorg model.[7, 8] Dit betekent dat iedere zorgverlener die met patiënten werkt basiskennis en -vaardigheden dient te hebben in het verlenen van palliatieve zorg, en dat in complexe gevallen ondersteuning gevraagd kan worden aan specialistische palliatieve zorgverleners. Het is daarom van belang dat kennis en vaardigheden adequaat worden aan bod komen tijdens de (medische) opleiding. Eerdere Nederlandse evaluaties over kennis en vaardigheden in de palliatieve zorg hebben aangetoond dat 30% van de artsen onvoldoende kennis had over pijnbehandeling, en dat 83% van de artsen extra onderwijs over opioïden en pijnbehandeling en over palliatieve sedatie op prijs zou stellen.[9, 10] Kennis en vaardigheden met betrekking tot palliatieve zorg waren nog niet in detail onderzocht bij Nederlandse geneeskundestudenten.

Generalistische zorgverleners dienen getraind te worden in het identificeren van patiënten die baat kunnen hebben bij een palliatieve zorg benadering. Dit omvat ook het herkennen van 'triggermomenten', gebeurtenissen die wijzen op achteruitgang of een verhoogde behoefte aan palliatieve zorg. Het herkennen van 'triggermomenten' stelt zorgverleners in staat om zorgdoelen te (her)overwegen en deze te bespreken met patiënten en familie.[11] Een belangrijk voorbeeld van een triggermoment is wanneer patiënten met een mogelijk levensbedreigende ziekte de Spoedeisende Hulp (SEH) bezoeken: SEH-getriggerde palliatieve zorg. Het is aangetoond dat patiënten die SEH-getriggerde palliatieve zorg ontvingen een betere kwaliteit van leven hadden dan patiënten die standaard zorg ontvingen.[12, 13]

De Surprise Question, “Zou het mij verbazen als deze patiënt binnen een jaar overlijdt?”, wordt gebruikt als instrument om patiënten met palliatieve zorgbehoeften vroegtijdig te identificeren.[14] Het gebruik ervan als screeningsinstrument wordt aanbevolen door het Nederlands Kwaliteitskader Palliatieve Zorg.[2] De prognostische waarde van de Surprise Question op de SEH was al onderzocht bij patiënten met hartfalen en bij oudere patiënten.[15, 16] Er was nog geen onderzoek gedaan bij patiënten met gevorderde kanker die de SEH bezochten.

Na identificatie van patiënten die baat kunnen hebben bij een palliatieve zorgbenadering, dienen zorgverleners te onderzoeken welke behoeften aan palliatieve zorg patiënten en hun familie hebben, om palliatieve zorg op maat te kunnen bieden. Een volledig onderzoek bevat een multidimensionale beoordeling van de symptoomlast en de informatiebehoefte. Het Expertisecentrum Palliatieve Zorg van het Leids Universitair Medisch Centrum, Nederland, maakt gebruik van de Leidse Gesprekshulp Palliatieve Zorg (LGP) als leidraad voor hun consulten met patiënten en familie. De LGP bestaat uit twee delen. Het eerste deel bestaat uit het Utrecht Symptoom Dagboek, een vertaalde en aangepaste Edmonton Symptoombeoordelingsschaal.[17, 18] Het Utrecht Symptoom Dagboek wordt gebruikt voor het meten en monitoren van symptoomlast in de palliatieve fase op numerieke beoordelingsschalen van 1-10 van twaalf symptomen die vaak voorkomen in de palliatieve fase. Het tweede deel is een lijst met onderwerpen en vragen (hierna genoemd: gesprekshulp) over palliatieve zorg, een Nederlandse bewerking van de versie ontwikkeld door Clayton et al.[19] Patiënten en familie kunnen in de gesprekshulp aangeven welke onderwerpen en vragen zij tijdens het consult willen bespreken. Patiënten en familie die de gesprekshulp hadden gebruikt, stelden twee keer zoveel vragen als degenen die dat niet hadden gedaan.[20] Voordat de studies uit dit proefschrift werden uitgevoerd, was er nog geen Nederlandse question prompt list over palliatieve zorg geëvalueerd. Bovendien was de relatie tussen symptoomlast en informatiebehoeften, en wat dit zou kunnen betekenen voor gesprekken op maat over palliatieve zorg, nog niet eerder onderzocht.

Hierboven staan belangrijke elementen van palliatieve zorg beschreven: passend onderwijs, inzicht in het gebruik van triggermomenten, tijdige identificatie van patiënten die palliatieve zorg nodig hebben, en beoordeling van symptoomlast en informatiebehoeften. Om goede palliatieve zorg te verlenen is een proactieve benadering nodig. Dit proefschrift is gericht op het identificeren van mogelijkheden om patiëntgerichte en proactieve palliatieve zorg te verbeteren. De onderzoeksdoelstellingen van de studies in dit proefschrift waren de volgende:

1. Het beoordelen van de mate waarin levenseindezorg wordt onderwezen op geneeskundefaculteiten in Nederland, en het vinden van mogelijkheden om de Nederlandse medische curricula te verbeteren.
2. Het onderzoeken van palliatieve zorgbehoeften en de mate van proactieve zorg bij patiënten met gevorderde kanker die in de laatste drie maanden van hun leven de Spoedeisende Hulp (SEH) bezochten.
3. Het beschrijven van het levenseindetraject en de kwaliteit van zorg van patiënten met een hematologische maligniteit die de SEH bezochten in de laatste drie maanden van hun leven, in vergelijking met patiënten met gevorderde kanker.
4. Het evalueren van de testkarakteristieken van de Surprise Question voor het identificeren van palliatieve zorgbehoeften bij patiënten met gevorderde kanker die de SEH bezoeken.
5. Het verband tussen symptoomlast en informatiebehoeften van patiënten die verwezen worden naar een consultteam palliatieve zorg in een ziekenhuis onderzoeken met behulp van de Leidse Gesprekshulp Palliatieve Zorg (LGP).
6. Het evalueren en doorontwikkelen van de gesprekshulp van de LGP om deze passend te maken voor gebruik door generalistische zorgverleners.

HOOFDSTUK 2. LEVENSEINDEZORG IN DE NEDERLANDSE MEDISCHE CURRICULA

Hoofdstuk 2 beschrijft een cross-sectionele studie naar de mate waarin levenseindezorg deel uitmaakte van de Nederlandse geneeskundeopleidingen. Er is gekozen voor een focus op levenseindezorg omdat dit beschouwd kan worden als een essentieel onderdeel van palliatieve zorg. Het onderzoek werd uitgevoerd in het academisch jaar 2015-2016. Een checklist met de essentiële domeinen van onderwijs in levenseindezorg werd samengesteld op basis van wetenschappelijke literatuur. De checklist werd gebruikt om het Nederlandse Raamplan Artsopleiding[21] en de medische curricula van de acht medische faculteiten in Nederland te beoordelen. Dit onderwijs omvatte acht bachelorstudies, acht masterstudies en keuzevakken. Studiecoördinatoren van bachelor- en mastercurricula werden benaderd om een vragenlijst in te vullen die was afgeleid van de checklist, en werden daarna geïnterviewd om toelichting te krijgen op hun antwoorden in de vragenlijst. De studiegidsen van alle medische faculteiten werden gebruikt om de keuzevakken te beoordelen. Het raamplan omvatte vier van de vijf domeinen van zorg rond het levenseinde. Geen van de acht medische faculteiten onderwees alle domeinen specifiek over zorg rond het levenseinde. De meeste aandacht werd besteed aan *psychologische, sociologische, culturele en spirituele aspecten*; *communicatie en gesprekstechnieken*; en *juridische en ethische aspecten*. Eén faculteit gaf een keuzevak dat alle essentiële aspecten naar de internationale normen bevatte. We concludeerden dat om het onderwijs over levenseindezorg te verbeteren, de vijf essentiële domeinen toegevoegd zouden moeten worden aan het Nederlandse Raamplan Artsopleiding, dat in 2019 herzien zou moeten worden. Daarnaast zouden medische faculteiten hun curricula moeten herzien en levenseindezorg als verplicht onderdeel van de medische curricula moeten aanbieden om geneeskundestudenten voor te bereiden op hun toekomstige medische praktijk.

HOOFDSTUK 3. PALLIATIEVE ZORGBEHOEFTEN VAN GEVORDERDE KANKERPATIËNTEN OP DE SPOEDEISENDE HULP AAN HET EINDE VAN HUN LEVEN: EEN OBSERVATIONELE COHORTSTUDIE

Inzicht in de levenseindetrajecten van patiënten met gevorderde kanker die de SEH bezoeken is van toegevoegde waarde in het kader van SEH-getriggerde palliatieve zorg. Hoofdstuk 3 beschrijft een mortality follow-back studie bij 420 patiënten met gevorderde kanker die de SEH bezochten tot drie maanden voor hun overlijden. Deze studie toonde aan dat patiënten met gevorderde kanker vaak de SEH bezochten terwijl zij nog ziektegerichte behandeling kregen. Slechts een paar patiënten hadden behandelbeperkingen. Dit kan hebben geleid tot een hoog percentage ziekenhuisopnames en sterfgevallen in het ziekenhuis in deze studie. Factoren die geassocieerd werden met naderend overlijden waren longkanker, neurologische verslechtering, dyspneu, hypercalciëmie, en geelzucht. Tijdige herkenning van patiënten met een hoog risico op naderend overlijden kan levenseindezorg bij patiënten met gevorderde kanker verbeteren. Om tijdige herkenning te vergemakkelijken, werd een stroomschema opgesteld dat het nemen van gerichte acties ondersteunt bij patiënten met gevorderde kanker en dringende palliatieve zorgbehoeften op de SEH.

HOOFDSTUK 4. LEVENSEINDETRAJECTEN VAN PATIËNTEN MET HEMATOLOGISCHE MALIGNITEITEN EN PATIËNTEN MET GEVORDERDE SOLIDE TUMOREN DIE DE SPOEDEISENDE HULP BEZOEKEN: DE NOODZAAK VAN EEN PROACTIEVE GEÏNTEGREERDE ZORG BENADERING

Palliatieve zorg op de SEH kan potentieel niet-passende zorg aan het einde van het leven voorkomen.[12, 13] Patiënten met een hematologische maligniteit (bloedkanker) krijgen vaker agressieve zorg aan het einde van het leven dan patiënten met een solide tumor.[22] Inzicht in signalen voor proactieve zorg kan helpen bij het verbeteren van palliatieve zorg op de SEH bij patiënten met een hematologische maligniteit. Hoofdstuk 4 presenteert een studie bij 78 patiënten met een hematologische maligniteit en 420 patiënten met een solide tumor die de SEH bezochten in de laatste drie maanden van hun leven. De studie was een ‘mortality follow-backstudie’, waarbij teruggekeken vanaf het overlijden van de patiënt, naar het traject voor het overlijden. Het doel was om de levenseindetrajecten en de kwaliteit van levenseindezorg van deze patiënten te vergelijken aan de hand van vijf van Earl et al.’s kwaliteitsindicatoren van levenseindezorg: intensieve antikankerbehandeling korter dan drie maanden geleden ondergaan, het aantal SEH bezoeken in de laatste zes maanden, overlijden in het ziekenhuis, overlijden op de intensive care unit (ICU), en overlijden in het ziekenhuis. Kenmerken van proactieve zorg waren 1) communicatie over de toestand van de patiënt tussen een arts of consulent palliatieve zorg uit het ziekenhuis en de huisarts van de patiënt; 2) proactieve zorgplannen; 3) en behandelbeperkingen voor het huidige SEH-bezoek. Patiënten met een hematologische maligniteit hadden voor hun SEH-bezoek minder vaak gesproken over behandelbeperkingen dan patiënten met een solide tumor. Sinds hun SEH-bezoek ontvingen patiënten met een hematologische maligniteit agressievere levenseindezorg en werden ze vaker opgenomen in het ziekenhuis na hun SEH-bezoek. Ze stierven vaker in het ziekenhuis, op de intensive care, of op de SEH. We bevelen aan om zowel patiënten als SEH-personeel te ondersteunen met een tweesporenbeleid, een zorgmodel voor vroege integratie van palliatieve zorg in combinatie met curatieve hematologische behandeling. Het tweesporenbeleid is erop gericht patiënten met een hematologische maligniteit tijdig voor te bereiden op de dood als mogelijk gevolg van hetzij hun levensbedreigende ziekte, hetzij een zware behandeling, wanneer zij hun wensen nog kunnen uiten.

HOOFDSTUK 5. SURPRISE QUESTION EN FUNCTIONEREN (PERFORMANCE STATUS) GEVEN URGENTIE VAN PALLIATIEVE ZORGBEHOEFTEN AAN BIJ PATIËNTEN MET GEVORDERDE KANKER OP DE SPOEDEISENDE HULP: EEN OBSERVATIONELE COHORTSTUDIE

De Surprise Question (SQ), "Zou het mij verbazen als deze patiënt binnen een jaar zou overlijden?", is een methode om patiënten met palliatieve zorgbehoeften te identificeren.[14] De SQ wordt gesteld en beantwoord door de zorgverlener. Een "niet verrast" (NS)-antwoord is een indicatie voor mogelijke palliatieve zorgbehoeften, die verder moeten worden geëvalueerd. Een meta-analyse van Downar et al. toonde aan dat de SQ mogelijk geen afdoende screeningsinstrument is voor overlijden binnen één jaar in de totale populatie van patiënten met kanker in een gevorderd stadium.[23] Het ontbrak aan sensitiviteit, waardoor het aantal patiënten met palliatieve zorgbehoeften onderschat werd. De SQ kan nauwkeuriger zijn in combinatie met andere indicatoren van palliatieve zorgbehoeften, zoals symptomen die voorkomen in de palliatieve fase, het functioneren (performance status), en indicatoren van toegenomen gebruik van formele en informele zorg. Hoofdstuk 5 bevat een observationele cohortstudie bij 245 patiënten met gevorderde kanker die in 2013 en 2014 de SEH bezochten met als doel de testkarakteristieken van de SQ te evalueren. De toevoeging van andere klinische factoren die voorspellend zijn voor overlijden werd bestudeerd om te kijken of deze de testprestaties van de SQ kunnen verbeteren. De resultaten laten zien dat de SQ de volgende testkarakteristieken had: sensitiviteit van 89%, specificiteit van 40%, positief voorspellende waarde van 85%, negatief voorspellende waarde van 50% en een c-index van 0.56. Bij patiënten bij wie het artsen niet zou verbazen als zij binnen een jaar zouden overlijden, was ECOG performance status 3-4 een onafhankelijke voorspeller voor naderend overlijden. Toevoeging van ECOG performance status 3-4 als tweede stap aan de SQ verbeterde de c-index (0,65), specificiteit (92%) en positief voorspellende waarde (95%) ten koste van sensitiviteit (40%) en negatief voorspellende waarde (29%). Performance status kan een waardevolle toevoeging zijn aan de SQ om te differentiëren in prognose en dus in urgentie van palliatieve zorgbehoeften. Op de SEH kan de combinatie van als eerste, de SQ, en als tweede, de performance status fungeren als een trigger om palliatieve zorg te starten naar de wensen van de patiënt. Een model dat de SQ en de performance score omvat werd geconstrueerd om te ondersteunen welke acties geschikt zijn voor welke urgentie van palliatieve zorgbehoeften bij patiënten met gevorderde kanker die de SEH bezoeken.

HOOFDSTUK 6. INVENTARISEREN VAN SYMPTOOMLAST EN INFORMATIEBEHOEFTEN VAN PATIËNTEN HELPT OM PALLIATIEVE ZORG CONSULTEN OP MAAT AAN TE BIEDEN: EEN OBSERVATIONELE STUDIE

De relatie tussen door de patiënt gerapporteerde symptoomlast en informatiebehoefte is niet eerder onderzocht. Een observationele studie bij 321 patiënten verwezen naar een consultatieteam palliatieve zorg die tussen 2013 en 2018 een LGP hadden gebruikt, werd uitgevoerd om inzicht te geven in de relatie tussen door de patiënt gerapporteerde symptoomlast en informatiebehoefte. Het tweede doel was om de relatie tussen palliatieve fase (ziektegericht versus symptoomgericht), en symptoomlast en informatiebehoeften te bestuderen. Ingevulde LGP's werden gebruikt voor de analyses. De meeste patiënten in deze studie hadden kanker. Patiënten rapporteerden de hoogste mediane symptoomlast voor *Vermoeidheid* en *Minder eetlust*. De meeste informatiebehoeften waren er over *Vermoeidheid*, *Behandelopties voor toekomstige klachten* en *Te verwachte klachten*. Patiënten hadden meer informatiebehoeften over symptomen waarvoor zij klinisch relevante last rapporteerden, of die zij als prioriteit hadden aangemerkt. Patiënten die milde symptoomlast rapporteerden, gaven echter ook regelmatig aan dat ze informatie over dat symptoom wilden. Patiënten in de symptoomgerichte fase wilden vaker informatie over hoe zij de zorg thuis of in een hospice kunnen regelen, terwijl patiënten in de ziektegerichte fase meer informatie wilden over hoe de behandeling hun kwaliteit van leven kan beïnvloeden. Deze studie toonde aan dat assessment van symptoomlast alleen niet voldoende is om na te gaan over welke onderwerpen patiënten meer informatie nodig hebben of waarover zij zich zorgen maken.

HOOFDSTUK 7. NIET-SPECIALISTISCHE PALLIATIEVE ZORG - VOORBEREIDING VAN EEN QUESTION PROMPT LIST: ERVARINGEN VAN PATIËNTEN, FAMILIE EN ZORGVERLENERS.

Hoofdstuk 7 is een mixed-methods studie uitgevoerd in 2017-2018 om het gebruik van de question prompt list van de LGP te evalueren en door te ontwikkelen. Aan de hand van 35 interviews (18 met patiënten en familie, en 17 met zorgverleners) werd het gebruik van de question prompt list geëvalueerd en hun suggesties hielpen om de question prompt list te verbeteren. Tweeëndertig consulten werden opgenomen en uitgeschreven om na te gaan in welke mate onderwerpen die patiënten en familie hadden aangegeven te willen bespreken, ook daadwerkelijk werden besproken tijdens het consult. Uit de resultaten blijkt dat patiënten, familie en zorgverleners de question prompt list als relevant, begrijpelijk en volledig beschouwden. Patiënten en familie legden uit dat het gebruik van de gesprekshulp vóór het consult hun gedachten structureerde en hen hielp bij het stellen van hun vragen tijdens het consult. Het hielp hen om weer een gevoel van regie te krijgen. Hoewel het gebruik van de gesprekshulp sterke emoties kon oproepen, beschreven ze dat hun echte uitdaging was om te aanvaarden dat ze een patiënt in de palliatieve fase waren. Zorgverleners vonden dat de question prompt list hen kon helpen als geheugensteuntje bij het bespreken van onderwerpen. Tijdens consulten in het ziekenhuis met consulenten palliatieve zorg werden onderwerpen die patiënten en familie hadden aangegeven vaak besproken, maar ook onderwerpen gericht op het (re)organiseren van het leven thuis werden besproken. Met behulp van feedback van patiënten, familie en zorgverleners werden de LGP aangepast en een werkinstructie geschreven om zorgverleners te ondersteunen bij het adequaat en optimaal gebruiken van de question prompt list.

HOOFDSTUK 8. ALGEMENE DISCUSSIE

Hoofdstuk 8 bestaat uit vijf delen. In deel 1 wordt een overzicht gegeven van de studies die in dit proefschrift zijn opgenomen. Deel 2 gaat in op de gebruikte onderzoeksmethoden. In deel 3 worden de implicaties van de bevindingen gepresenteerd uitgaande van het concept proactieve palliatieve zorg. Aan de hand van de definities van ‘proactiviteit’ en ‘palliatieve zorg’ kunnen drie kernprincipes van proactieve palliatieve zorg worden geïdentificeerd:

- bevordering van kennis en zelfinitiatief in de triade van patiënt, familie en zorgverlener;
- de intentie om goede resultaten te behalen en (toekomstige) problemen te voorkomen;
- vooruitdenken om te kunnen handelen voordat dingen gebeuren.

In dit proefschrift wordt beschreven hoe kennis en zelfinitiatie van de triade patiënten, hun familie en zorgverleners kan worden bevorderd. Studenten geneeskunde moeten voldoende onderwijs krijgen om hen voor te bereiden op hun klinische praktijk, waarin ook patiënten in de laatste fase van hun leven aan bod komen. Gesprekshulpen zoals de Leidse Gesprekshulp Palliatieve Zorg zetten patiënten en familie in hun kracht, wat bijdraagt aan hun kennis en zelfinitiatief.

Om de intentie te hebben om goede resultaten te behalen en (toekomstige) problemen te voorkomen, dienen zorgverleners kennis te hebben over wat signalen en indicatoren voor goede kwaliteit en proactieve palliatieve zorg zijn. Indicatoren voor kwaliteitsvolle en proactieve palliatieve zorg worden geïllustreerd aan de hand van het voorbeeld van patiënten met een hematologische maligniteit. Bij kwaliteitsvolle en proactieve palliatieve zorg hoort vroege markering van patiënten die de spoedeisende hulp bezoeken. Een bezoek aan de spoedeisende hulp kan een aanleiding zijn om de doelen van de zorg te bespreken en het herkennen van deze aanleiding ondersteunt passende zorg.

Het gebruik van een tweesporenbeleid en het bespreken van toekomstscenario's zijn belangrijke componenten in 'vooruitdenken om te kunnen handelen voordat dingen gebeuren'. Persoonsgerichte communicatiemethoden en gesprekshulpen kunnen het gebruik van een tweesporenbeleid en het bespreken van toekomstscenario's ondersteunen.

Het hoofdstuk geeft verder, vanuit de kernprincipes van proactieve palliatieve zorg, een aantal aanbevelingen voor het doen van verder onderzoek (deel 4) en voor onderwijs, klinische praktijk en beleid (deel 5).

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* The authors J. de Bruin and M.J. Verhoef contributed equally to the manuscript.
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N-27. Communicated Values, Wishes and Needs of Hospitalized Patients and their Loved Ones: A Survey among Clinicians
Sita de Vries, Mary-Joanne Verhoef, Farhad Akbari Moqadam, Ginette Hesselmann, Ellen J.M. de Nijs, Sigrid Vervoort, Saskia Teunissen, Yvette M. van der Linden, Everlien de Graaf
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LBA-COV-019. Learning from experiences, wishes and needs of non-covid metastatic colorectal cancer outpatients during the COVID-19 pandemic, a mixed method study

Everlien de Graaf Everlien, Sita de Vries, Mary-Joanne Verhoef, Ginette Hesselmann, Ellen J.M. de Nijs, Yvette M. van der Linden, Saskia Teunissen

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CURRICULUM VITAE

Mary-Joanne Verhoef was born on 25 March 1991 in Utrecht, the Netherlands. She went to the Cathedral Choir School in Utrecht until 2002, graduated from high school at Christelijk Gymnasium in Utrecht in 2009 and studied Medicine at Leiden University Medical Center from 2009 until 2017. During her bachelor studies, she became involved in organizing a students' project called 'Dying, a Human Thing' via the International Federation of Medical Students' Association in Leiden. The project aimed at filling the curricular gap regarding education on end-of-life care by offering an extracurricular course. In 2015-2016, she studied the post-initial master Vitality and Ageing. The master thesis she wrote with colleague Josefien de Bruin is included in Chapter 2 of this thesis. During the master Medicine, she was a research intern with the Center of Expertise in Palliative Care of Leiden University Medical Center, where she supported data collection of the PASEMECO-project. After her medical studies in 2017, she worked as a PhD-student for the Center of Expertise in Palliative Care of Leiden University Medical Center, under supervision of prof. dr. Yvette M. van der Linden. Studies that were part of the PhD-project are presented in this thesis. Activities undertaken during the PhD-trajectory include participation in the platform for qualitative research of the hospital and the supervision of research interns. During her PhD-trajectory, she followed a three-year minor in Classical Violin at the Royal Conservatoire in the Hague with Professor Theodora Geraets. Her final recital was graded with an 8.5. Also, she was the main organizer of EMSOC (European Medical Students' Orchestra and Choir), an international project choir and orchestra that took place in the Hague in 2018. She took part in several courses of the bachelor Philosophy at Leiden University. In 2020, she started working as a physician (ANIOS) in elderly care and simultaneously started as a local project manager and researcher of the project 'In Gesprek komen en in Gesprek blijven' at the Center of Expertise in Palliative Care of Leiden University Medical Center. As a physician, she participated in the working group on palliative care of the Topaz foundation (specialized in institutional elderly care) and in the working group on research in palliative care for persons with dementia for the UNC-ZH (Universitair Netwerk voor de Care sector Zuid-Holland). In 2021, she started working as a resident (AIOS) in elderly care at Leiden University Medical Center. During her residency, she took part of the steering group on palliative care of the Topaz foundation. After her PhD-graduation, she will continue finishing her residency in elderly care and she will stay involved in palliative care studies regarding proactive communication with the Center of Expertise in Palliative Care of Leiden University Medical Center. As a classical viol(in) ist, she is a member of several chamber music and orchestral ensembles including the World Doctors Orchestra and European Doctors Orchestra. Since 2018, she plays violin with the Palliators, a cover band with colleagues who work in palliative care.

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